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THE EXPERIENCES AND UNDERSTANDING  
OF THE MENSTRUAL CYCLE  
IN WOMEN WITH LEARNING DISABILITIES

A thesis submitted in partial fulfilment of the requirements  
of the Open University for the degree of Doctor of Clinical Psychology

SEPTEMBER 2000

In the region of 20,000 words  
(excluding references and appendices)

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# **ABSTRACT**

## **Background**

During the last 30 years there has been a proliferation of research into the menstrual cycle with particular focus on pre-menstrual syndrome (PMS). The research, however, has not specifically addressed the experiences of women with learning disabilities with regards to the menstrual cycle. The extent to which their experiences resemble those of non-disabled women is therefore not known.

## **Aims**

The research aimed to compare menstrual cycle change in women with learning disabilities with those of a group of non-disabled women. A further aim was to explore the subjective experiences of women with learning disabilities and to relate the findings to the research evidence pertaining to non-disabled women.

## **Design**

The study was cross sectional and employed both within and between groups comparisons. There were two parts to research and both quantitative and qualitative methods were used.

## **Method**

Quantitative 34 women with learning disabilities and 50 non-disabled women completed a modified form of the Menstrual Distress Questionnaire (MDQ) regarding changes experienced across the menstrual cycle.

Qualitative A semi-structured interview was used to explore the views of eleven women with learning disabilities towards the menstrual cycle in general and menstruation in particular.

## Results

Both groups reported significant changes in mood and behaviour occurring across the menstrual cycle. Between group analysis revealed that control group reported significantly more change in the pre-menstrual phase of the cycle whereas the client group reported more change during menstruation.

Analysis of the interviews indicated that women with learning disabilities have little knowledge of the menstrual cycle and experience menstruation as a debilitating condition.

## Conclusion

The focus on PMS in menstrual cycle research does not address the concerns of women with learning disabilities who appear to experience more difficulty with menstruation. The clinical and service implications are discussed and directions for future research suggested.

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## **CHAPTER ONE : INTRODUCTION**

### **1.1 Outline**

The research reported here is concerned with how women with learning disabilities experience the menstrual cycle. This chapter will discuss the question of gender in relation to women with learning disabilities, including relevant health care issues. Research evidence pertaining to the menstrual cycle will be reviewed before considering the evidence specifically applicable to women with learning disabilities. An exploration of the methodological difficulties in undertaking research both in to the menstrual cycle and also with people with learning disabilities will follow before posing the rationale and the research questions.

### **1.2 Gender and Women with Learning Disabilities**

#### **1.2.1 Service Provision**

The principles of normalisation, which were forceful in shaping service provision following the closure of the long stay hospitals, were responsible for many significant benefits for people with learning disabilities (Williams & Nind, 1999). These included increased opportunities for “an ordinary life” in the move to community based services and the emphasis on presence and participation within the community (Tyne & O’Brien, 1981; Williams & Nind, 1999).

There is no doubt that very real benefits accrued but critics have drawn attention to the fact that the “underlying ideology of normalisation” ignores issues of gender, sexuality, age and race (Williams & Nind, 1999). Within services, lip service was paid to the promotion of gender specific roles and the need for “sexually appropriate behaviour” (Wolfensberger, 2000). In practice, however, neither men nor women were accorded full status as adults and services were developed on the presumed assumption that men and women responded to events and experiences in the same way. Consequently, the denial of a gendered identity permeated services and the men and women living in service settings were seen as genderless and treated accordingly (Brown & Smith, 1989; Clements, Clare & Ezelle, 1995; Burns, 2000).

#### 1.2.2 \*Ignoring Gender

Williams & Nind (1999) note that, with a few exceptions, there has been a lack of attention given to women with learning disabilities, not just in mainstream learning disability research, but also within feminist and disability research. The reasons possibly lie within the dominant agendas of the respective movements: feminist research has tended to be concerned with projecting a strong image and in challenging the role of women as ‘taken for granted carers’ (Brown & Smith, 1989) which has excluded those who are also ‘cared for,’ whilst the disability movement has been dominated by the concerns of those with a physical disability. As a result the specific needs of women with learning disabilities have been ignored, perhaps on the erroneous

\*Gender is taken to refer to the way in which the views, experiences and needs of men and women differ and that these differences are not accounted for on biological grounds alone (Clements, Clare & Ezelle, 1995).

assumption that they do not 'want things other women want, or mind about things other women mind about' (Brown, 1996). An ungendered life, however, is unusual, denies the experiences of women and may seriously disadvantage them within services by allowing unsafe or inappropriate placements to be made (Burns, 1993; Brown, 1996).

Within the last ten years there has been a gradual change in this position and the need to address issues specific to women in learning disability services is now being recognised. Attention has been given to their experiences of sexuality (Brown, 1994; McCarthy, 1993; 1999), to their experiences as mothers (Booth & Booth, 1994; Edmonds, 2000; Elms, 2000) and to the pressures they may experience to conform to an idealised body image (McCarthy, 1998a). When asked, women with learning disabilities have been shown to have a clear appreciation of gender, drawing strongly on stereotypes which portray women not only as biologically determined but also inferior to men (Scior, 2000). Women with learning disabilities may therefore experience a "double jeopardy"; of being discriminated against both because they are women and because they are "disabled women" (Scior, 2000), a consideration which may be particularly relevant when attempting to access generic services (Baum & Burns, 2000).

### 1.2.3 Gender and Health Care

The closure of the long stay hospital meant that many people either moved to, or remained within, a local community. There was an emphasis on integration within the community and the expectation that people with learning disabilities would access

generic services, including primary health care services, in the same way as non-disabled people (Tyne & O'Brien, 1981; Nightingale, Ditchfield, Pepperrell, Murphy & Gee, 1998).

Research evidence suggests that access to primary health care services remains a problem for people with learning disabilities with their needs not being appropriately addressed within the system (Wilson & Haire, 1990; Rodgers, 1994). This poses particular difficulties for women who are further disadvantaged by lack of knowledge of their body in general and of the reproductive cycle in particular (McCarthy, 1998a; Nightingale *et al.*, 1998).

There is evidence, for example, that women with learning disabilities are discriminated against in accessing preventative health screening such as cervical screening (Nightingale, 2000). Practitioners within primary services displayed considerable variation in their attitudes; some areas of good practice were identified but other health service practitioners revealed stereotyped ideas as to the status of the women concerned which meant that they were not routinely offered an appointment for screening (Nightingale, 2000). These views persisted despite the emphasis placed on access to health screening for women with learning disabilities in government policy documents throughout the 1990s (Department of Health, 1992; 1998).

The attention given to the reproductive cycle in women with learning disabilities has adopted a predominantly mechanistic approach with the emphasis being on menstrual management and the prevention of pregnancy in women with severe learning disabilities (Carlson & Wilson, 1995; McCarthy, 1998a). There has been little research

into how women with learning disabilities experience other aspects of the reproductive cycle and their knowledge of the menarche, the menstrual cycle and the menopause is simply not known (Clements *et al*; 1995; Brown, 1996; Williams & Nind, 1999). This contrasts sharply with the attention given in mainstream research during the last 30 years to women's experiences of the menstrual cycle and the impact of these attitudes on the way in which a woman will feel about her body (Choi, 1999).

### **1.3 Menstruation and the Menstrual Cycle**

#### **1.3.1 Menstrual Facts**

Menstruation is one point in the continuous cycle of hormonal changes that occur in virtually all women from puberty to the menopause and is the outward, visible evidence of a woman's ability to reproduce (Walker, 1997).

In Western cultures girls experience the menarche somewhere between 10 and 16 years of age with 13 being the average (Coleman & Hendry, 1990). Throughout the last century the onset of menstruation has decreased in industrial societies at the rate of one month for every decade and may be still decreasing. The reasons for this are not known although improvements in health and diet are generally held to be responsible (Coleman & Hendry, 1990). Bancroft (1995) suggests that an earlier menarche, fewer children and a decrease in prolonged breast feeding mean that women experience more menstrual cycles than they would have done in the past and that a woman may now spend between 1/5 and 1/7<sup>th</sup> of her life menstruating.

The average cycle is usually given as 28 days but this conceals a wide variation both in individual women and in the same woman over time; in early adolescence the average cycle is 35 days which reduces to 27 days by the time the woman is in her early forties. The length then increases to 52 days towards the menopause (Walker, 1997). However, rather than comparing between women, epidemiological studies have suggested that each woman develops a cycle that is normal for her in terms of length, number of days of menstrual loss and the amount lost in each cycle. This then forms a “bench mark” against which changes are measured (McNeil, 1992).

In adolescent girls the first menstrual period is still seen as significant, even though it usually occurs towards the end of the cycle of changes involved in puberty which include breast development, widening of the hips and the growth of body hair (Ussher, 1989). The extent, however, to which girls are prepared for this event remains variable. Education still tends to focus more on hygiene and the biological processes rather than on the social and psychological processes involved in the change from child to woman and to therefore be divorced from the experience and concerns of most girls. This means that many are still unprepared for the event itself (Ussher, 1989).

### 1.3.2 Attitudes to Menstruation

Whilst some positive attitudes to menstruation have been recorded (Grahm, 1992; Walker, 1997) the overwhelming discourse remains negative (Ussher, 1989; Lovering, 1995). Girls may be better prepared in the 1990s than they were in the 1950s but this

still tends to relate more to factual knowledge, biology and hygiene than the actual experiences and feelings of the girl in question (Ussher, 1989; Kissling, 1995).

Considerable ambivalence still attends the menarche: the girl is told that it is a positive experience, that it celebrates the transition from child to woman but she also receives the message that it is to be kept secret, that it is not to be discussed openly and especially not with men (Ussher, 1989). Research evidences suggests that adolescents of both sexes view menstruation with distaste and that girls are particularly embarrassed by discussion of the topic in mixed groups (Lovering, 1995; Kissling, 1996).

It is possibly because of its inextricable links with sexuality and reproduction that menstruation gives rise to so much ambivalence, especially at the time of the menarche. Ussher (1989) comments that too often menstruation is seen in relation to conception and an unwanted pregnancy and that this anxiety on the part of parents results in sexuality "being defined in terms of heterosexual contact, penetration and impregnation" (Ussher, 1989).

Menstruation therefore is more than just a biological event, it is also a socially constructed one, reflecting the attitudes and beliefs of the prevailing culture (Parlee, 1973; Laws, Hey & Eagen, 1985; Ussher, 1989; Rodin, 1992 and others). In western cultures the way in which menstruation has been used to define women as subordinate to men is illustrated by the literature pertaining to pre-menstrual syndrome.



### 1.3.3 Pre Menstrual Syndrome [PMS]

The phrase 'pre menstrual tension' was first used to describe a cluster of symptoms (tension, restlessness, irritability and hostility) occurring between two and four days prior to the onset of menstruation (Frank, 1931). It was later renamed 'pre- menstrual syndrome' as the symptoms described were reported to encompass more than just tension (Greene & Dalton, 1953; Dalton, 1984).

In fact there is no universally agreed definition of PMS and, with over 150 symptoms having been attributed to the syndrome, it is almost impossible to operationalise (Choi, 1999). The debate over aetiology continues; there is no evidence for it being an hormonal disturbance and no one treatment has been shown to be successful for more than a few months (O'Brien, 1993; Bancroft, 1995). The political nature of PMS has also been long debated, the argument being that PMS is frequently used by men to reinforce stereotypes of femininity. Any behaviour that appears to be counter to the acceptable image of feminine behaviour can then be ascribed to a biological cause and essentially invalidated (Laws, Hey & Eager, 1985; Rodin, 1992).

Despite the compelling arguments for the social construction of PMS many women continue to report that they experience considerable adverse change in the pre-menstrual period and this cannot be ignored (Swann & Ussher, 1995). Current menstrual cycle research is at an impasse between the proponents of the bio-medical discourse and the socio-political discourse with neither one position being able to provide a satisfactory explanation (Swann, 1997). An integration of the two positions into a bio-psycho-social model which recognises that PMS is an interaction of both

internal and external events may provide a way forward for research in to PMS (Ussher, 1992; Swann, 1997).

#### 1.3.4 The Menstrual Cycle: a theoretical perspective

In a review of the research regarding the menstrual cycle and which could broadly be conceptualised as 'psychological' Walker (1997) suggests that there are three identifiable approaches to which she gives the labels 'mainstream', 'liberal feminist' and 'post modern'.

The mainstream approach applies research interests already existing within psychology to the menstrual cycle. In this, the menstrual cycle has been treated as an independent variable which might impact on the phenomenon under consideration. Such research adopted a nomothetic approach and used experimental methods to investigate hypotheses (Swann, 1997; Walker, 1997). Many of the concerns, however, have much in common with those of bio-medical research and, as such, do not offer a wholly psychological perspective of menstrual cycle research (Walker, 1997).

Liberal feminists have challenged the negative way in which the menstrual cycle, and, more particularly, PMS, is depicted by drawing attention to the political and social construction of PMS (Parlee, 1973, 1974; Laws, Hey & Eagen, 1985; Rodin 1992). Walker (1997) suggests that liberal feminist approaches have been of considerable value in highlighting the way in which cultural perceptions of PMS can influence responses to questionnaires, and in challenging the use of PMS as a diagnosis by demonstrating that cyclical changes are not universal. They are limited, however, by

the use of research methods of traditional science and by the lack of attention given to individual experiences.

Within the last ten years a new theoretical framework, labelled “post modern” has been proposed (Walker, 1997; Ussher 1999). This approach is concerned with subjective experiences and is more likely to utilise qualitative research methods. Its central point is the view that women are worthy of study and what they have to say about their lives is important (Henwood & Pidgeon, 1995; Swann & Ussher, 1995). Such approaches raise the hopes that *“psychologists at the turn of the twenty first century will be asking different questions about menstruation from those of psychologists at the turn of the twentieth century”* (Walker, 1997).

#### **1.4 Women with Learning Disabilities and the Menstrual Cycle**

##### **1.4.1 Research Evidence**

There has been little published research into the experiences of the menstrual cycle in women with learning disabilities. Physiologically there are few reported differences between women with learning disabilities and the general population. The menarche is reported to occur at a later age than for the mean of the general population (Culley, 1974) but more recent studies have shown this to be as little as 13 months overall (Evans & Nckinlay, 1988). The evidence found that girls with Downs syndrome formed an identifiable sub group and that they experienced the menarche 11 months earlier than for the normal population whilst girls with a non-specified learning disability had a mean menarcheal age 21 months later than the normal population. All

girls in this study, however, attended schools for those with severe disabilities so that it is not known whether or not this delay in the menarche applies to all women with a learning disability. Once established, menstrual function appears to mirror that of the general population although there is some indication that women with Downs syndrome also experience the menopause between one and two years earlier than the mean for the general population (Carr & Hollins, 1995; Schupf, Zigman, Kapell, Lee, Kline & Levin, 1997). The findings of an earlier menarche and a correspondingly earlier menopause in women with Downs syndrome provide supporting evidence for the 'early ageing' explanation for the increase in dementia seen in people with Downs syndrome.

One area that has been the focus of attention is the investigation of a correlation between reports of challenging behaviour and the pre-menstrual phase of the cycle. From clinical experience and reports (Becker, 1999, personal communication) if a woman presents with challenging behaviour then staff will frequently attribute this to menstruation and seek medical intervention rather than consider other functions to the behaviour.

In a small study of nine women with severe learning disabilities and challenging behaviour, Taylor, Rush, Helrich & Sandman (1993) found some evidence of an apparent association between self injurious behaviour and the phase of the menstrual cycle. There was no increase in self injurious behaviour pre-menstrually but a small increase both during and immediately after menstruation. The size of the study and the fact that there are no other reports of such a correlation does mean that it is impossible to draw any firm or more general conclusions from this study.

A larger study retrospectively considered reports of aggressive behaviour (from incident forms) and related these to the menstrual cycle of 118 women with a severe disability and in institutional care (O'Dwyer & Friedman, 1995). They found no evidence of an increase in aggression in either the pre-menstrual phase or perimenstrual phase of the cycle. In this study the highest rates of aggression occurred in women with primary amenorrhoea, of whom 50% were also receiving anti-psychotic medication. This suggests that factors other than hormonal changes related to the menstrual cycle were a mitigating influence in the reported incidents.

Despite such reports there is still a tendency to construe aggressive and self injurious behaviour as being associated with the menstrual cycle. Elkins (1994) reported on a clinic established at the Universities of Michigan and Tennessee which was held to be a model for meeting the health care needs of women with learning disabilities in relation to reported difficulties with their menstrual cycle. He noted that 15% of the first 350 women seen at the clinic presented with pre-menstrual syndrome "unusual in its severity", although this is not defined further. He also noted that a high percentage of women had menorrhagia (excessively heavy menstrual blood loss) and that "menstrual hygiene was often a severe problem for care providers or families" (Elkins, 1994). Reports such as these raise a number of concerns which need consideration:-

- I. The "diagnosis" of menorrhagia was made by the carer/family member who apparently experienced difficulties in managing menstrual flow and was accepted as such by the clinic staff, with no attempts at verification.

II. The attribution of increased aggression immediately prior to the menstrual cycle was again made by staff with no reference to the woman herself or to other factors which may have been implicated.

In this clinic, however, management tended to follow a medical model with medication being recommended and cautious support given to an hysterectomy if medication proved unsuccessful (Elkins, 1994).

This is not to suggest that menstruation does not pose particular difficulties for some women with severe learning disabilities. Such difficulties, however, are more likely to centre on the practical aspects of menstrual management, particularly in achieving independence in changing pads and difficulty in communicating preferences as to management approach (Carlson & Wilson, 1996). Whilst this is undeniably an issue for both the woman and, in some cases, her family/carers, it does mean that the experience of menstruation for women with learning disabilities, regardless of degree of disability, has not really been considered.

#### 1.4.2 Control of Menstruation

The anxieties raised by menstruation for both families and carers of women with learning disabilities means that its control by both surgical and pharmaceutical methods has been a major issue in services. Taylor & Carlson (1993) note that this has been documented as occurring in a number of countries including the USA, Canada, Finland and the UK. In their examination of legal trends in Australia they reviewed nine cases where permission was sought from the family court of Australia for an hysterectomy to

be performed even though the woman in question was pre-menarcheal. The reasons for seeking the surgery were varied but all included the anticipation of difficulties rather than reporting a current problem. Menstruation was seen as potentially painful and difficult to manage and there were concerns as to possible pregnancy should the woman become sexually active (Taylor & Carlson, 1993). Perhaps surprisingly, in view of the fact that none of the girls had experienced the menarche and may therefore not have displayed the anticipated problems, all judges eventually sanctioned the operation in all cases.

The wish to control menstruation has been supported by a more recent study in the UK which found that a 'high proportion' of women were being prescribed contraceptive pills despite not being sexually active. The suggestion was that this was a means by which staff could either reduce or eliminate menstruation completely (McCarthy, 1998a). This suggests that young women are being subjected to long term medication or major surgery without evidence of a physiological or disease condition in order to control their menstrual cycle (Carlson & Wilson, 1996).

#### 1.4.3 The need for Research

The experiences of people with learning disabilities are now being given a voice and work is being undertaken on the experience of women with learning disabilities (Williams & Nind, 1999; Schwartz, 2000). However, this has tended to remain within the wider remit of 'gender identity' (Scior, 2000; Burns, 2000).

The proliferation of research adopting a feminist standpoint into the menstrual cycle during the last 10 years has virtually ignored women with learning disabilities and the extent to which they share experiences with all women regarding their bodies is simply not known (Brown, 1994; McCarthy, 1998a). This has implications not just for the women themselves but also carers and providers of services. It may not be sufficient to adopt a strategy which states that women with a learning disability will access generic services but then fail to make those services accessible to the women in question. It cannot be assumed that the findings from research on non learning disabled women do, indeed, apply to the group in question. Rather there is a need for comprehensive research which seeks to address the experiences of the women in question with regards to their understanding and experiences of issues which directly impact on their lives (Brown, 1996).

## **1.5 Methodological Considerations**

### **1.5.1 Menstrual Cycle Research**

Undertaking research into the menstrual cycle is acknowledged to pose considerable methodological challenges (Walker, 1997; Choi, 1999). Until comparatively recently the emphasis has been on measurement and quantification of the variable under consideration with research being grounded in the approaches of traditional science.

The two main approaches within a psychological framework have been the use of retrospective questionnaire studies and prospective self report measures.



Retrospective studies have been criticised as they depend on the accuracy of the woman's recall of symptoms and responses may be influenced by prevailing cultural stereotypes regarding the menstrual cycle (Parlee, 1974; Richardson, 1990). For this reason prospective daily diary ratings of mood and behaviour have sometimes been seen as preferable as they minimise the demands on recall and hence the potential influence of negative stereotypes. They are, however, demanding on time and motivation to complete which means that they have a high rate of participants not completing the study (Richardson 1990).

It was recognised that prospective daily ratings would pose particular demands on women with learning disabilities in terms of time and help needed to complete the form and that this would make it difficult to recruit participants. It was also noted that not all reports have been critical of retrospective questionnaires; that the Menstrual Distress Questionnaire (MDQ) has been shown to have a high internal consistency and test-retest reliability (Moos, 1968; Markum, 1976; Hart, Coleman & Russell, 1987). In view of these considerations it was decided to use a modified form of the MDQ in this study but also to combine this with another method in an attempt to enhance validity.

One means of increasing the validity of research findings is to employ between methods triangulation. Triangulation is the term used to describe the combination of methods to measure a single construct in order to strengthen the findings and minimise any weaknesses inherent in the method (Redfern & Norman, 1994). In recognition of the possible limitations of the use of the MDQ a mixed design was employed in this

study whereby qualitative research methods were used to enhance the findings of the quantitative research.

#### 1.5.2 Research with People with Learning Disabilities

Undertaking research with people with learning disabilities raises complex methodological and ethical considerations. As the two interact (the ethical questions inevitably impacting on the methodology) they will be considered together. The over-riding question is how to involve the person in the research process in a way which addresses their interests and values their contribution (Stalker, 1998; Walmsley, 1998). The following points therefore need to be taken into when addressing the methodology.

##### 1.5.21 Nature of the Research

Questionnaire studies bring their own difficulties. Many people with a learning disability may be unable to read fluently or experience difficulty in understanding the questions. Facilitating communication may help but has been shown to pose additional challenges (Grove, Bunning, Porter & Olsson, 1999). The researcher may then be faced with the dilemma as to whether or not to exclude those who cannot read from the study or to offer assistance in interpreting the questionnaire which may bias the results. There are also very few questionnaires that have been standardised with people with learning disabilities which means that it is sometimes difficult to draw conclusions from the study.

People with learning disabilities also tend to acquiesce, to give an affirmative answer to questions, which is not solely accounted for by the degree of intellectual impairment experienced (Booth & Booth, 1994; McCarthy, 1998b). Stalker (1998) suggests that it is a reflection of the fact that many are not used to having control over their lives and are conditioned to respond affirmatively to staff.

If interviews are being used then the structure and format of the session warrants close attention. Booth & Booth (1994) noted that many of the participants in their studies were unable to cope with unstructured interviews, that there was a tendency to answer a question then wait for the next one and that they were simply not used to unstructured situations. Conversely, the structured interview does not allow for discussion of points of individual interest which means that the semi structured interview has emerged as the preferred option; it provides some structure in the form of prompts but still provides the flexibility to allow for discussion of areas of interest to the participant (McCarthy, 1999).

#### 1.5.22 Anonymity and Confidentiality

Anonymity and confidentiality can be difficult concepts to explain, especially to people who live in a public environment (e.g. residential services) and are accustomed to others assuming control over their lives (Stalker, 1998). There are, perhaps, fewer difficulties with confidentiality as it is possible to relate this to real people and situations in the life of the person and explain that they will not be told what was discussed in the interview. With regards to anonymity it is important that the person

understands that that their name, place of residence and any other identifiable features will not be apparent from the research (McCarthy, 1998b).

#### 1.5.23 Vulnerability within the Research Process

Many people with learning disabilities still lead relatively restricted lives and welcome any social contact (Booth, 1998; Stalker, 1998). This means that expectations may be raised regarding the relationship between the researcher and participant, which, if not met, can lead to the participant experiencing further rejection. There is a difference between being friendly and being friends that may not be easy for someone to understand. Before embarking on any social research it is therefore critical for the researcher to recognise that the relationship may not necessarily end with the research (Booth, 1998).

#### 1.5.24 Informed Consent

The importance of obtaining informed consent applies to all participants in any research (British Psychological Society, 1995). The traditional approach when working with people with learning disabilities was to approach the key worker (or someone well known to the person) to ask the person if they would be interested in taking part in the research. It was assumed that if the person did not wish to take part then they would be able to convey this to the keyworker. There is now some uncertainty in this regard: whilst Booth & Booth (1994) support this position McCarthy (1998b) suggests that being asked by a trusted person may increase the likelihood of acquiescence. Another potential pitfall with this approach is that it

assumes the description of the research provided to the key worker and thence conveyed to the potential participant is understood by both key worker and participant.

There are no easy solutions to these dilemmas and obviously there is a need for further work in this area. At this stage it is with the researcher to consider the ethical dilemmas inherent in their proposed study and to ensure that these are addressed with reference to current knowledge and good practice guidelines (British Psychological Society, 1995; Arscott, Dagnan & Kroese, 1998).

### **1.6 Summary and Aims of Present Study**

The importance of giving attention to gender specific issues in women with learning disabilities is now being recognised (Clements, Clare & Ezelle, 1995; Burns & Baum, 2000). To date, however, little attention has been given to how they understand events specific to women such as the functioning of their reproductive cycle (McCarthy, 1998a). This contrasts with the growth in research in the last 30 years with regards the functioning of the menstrual cycle in non-learning disabled women. The gap in understanding the needs of women with learning disabilities means that they may continue to be discriminated against in primary care services which are not equipped with the knowledge necessary to meet their needs (Nightingale, 2000).

The aim of the present study, therefore, was to address the experiences and understanding of the menstrual cycle in women with learning disabilities. A further aim was to explore the extent to which women with learning disabilities share experiences with non disabled women.

## **1.7 Research Questions**

### **1.7.1 Quantitative research questions**

- I. Do women with a learning disability report the same menstrual cycle changes as non-learning disabled women?
- II. Do women with a learning disability report a difference in symptoms occurring within the menstrual cycle?
- III. Does the reported pattern of change differ from non-learning disabled women?

### **1.7.2 Qualitative Research Questions**

Research questions were developed to address the aims of the study as described above:-

- I. What do the women know about the function of the menstrual cycle?
- II. What characterises their experience of the menarche?
- III. What are their current experiences of menstruation?
- IV. What characterises their attitudes to menstruation?
- V. What is their understanding of menstruation in regards to sexuality?

It was not intended to use these questions prescriptively but rather as a prompt to understanding the experiences from the point of view of the woman.

## **CHAPTER TWO : METHOD**

### **2.0 Design**

The study was cross sectional and employed both within and between groups design. There were two parts to the study and both quantitative and qualitative methodologies were used.

#### **2.1 Part One: Quantitative Design**

This investigated the way in which women with a learning disability reported changes across the menstrual cycle and compared them with responses given by a control group of non- learning disabled women. Attention was given to differences both between the groups and within groups as to pre-menstrual, menstrual and post-menstrual symptoms. The aim was to ascertain whether or not there was a significant difference in the experiences of women with learning disabilities when compared with the control group.

#### **2.2 Participants**

The client group (group one) consisted of women with a learning disability. Participants in group one were between 20-45 years of age and in receipt of learning disabilities services within the borough. Additional criteria required that:-

- I. The women were still experiencing a menstrual cycle.
- II. They were able to give informed consent to participation.

- III. They were able to distinguish between categories on the rating form.
- IV. They had not been seen by a consultant obstetrician on account of menstrual problems within the year prior to the study.

The control group (group two) consisted of non-learning disabled women who met the above criteria (1-4) and who were employed within the NHS trust in which the researcher worked.

## **2.3 Recruitment of Participants**

### **2.3.1 Group One (Clients)**

Approval for the study was obtained from the ethics committee of the Trust in which the research was to be undertaken (Appendix 1). Once this had been obtained a letter was sent to the joint service manager of the learning disability partnership within the borough to inform him of the proposed study and to seek permission to contact local providers (Appendix 2). Letters and a brief information sheet were then sent to all day and residential services within the borough and this was followed by a telephone call (Appendix 3).

There were considerable difficulties in recruiting sufficient numbers to group one. Reasons included:-

- I. The age constraints and the need to be experiencing a menstrual cycle.



- II. The day services in the borough are oriented at people with severe and profound learning disabilities who were unable to either give informed consent and/or to understand the questionnaire.
- III. The major 'Not for Profit' provider of residential services in the borough had only one woman within their service who met the required criteria (Appendix 4).
- IV. The questionnaire required women to be able to recall their last menstrual period and to be able to distinguish between categories. This further reduced the number of potential participants.

In practice this meant that women able to give consent and complete the questionnaire as well as meeting the other criteria were utilising a range of services and were not easy to access.

Consequently, in March 2000 the ethics committee of the re-configured trust was approached, seeking approval to extend this part of the study to the adjacent boroughs. Approval was received in May 2000 (Appendix 5) and the Learning Disability teams in those boroughs contacted by telephone followed by a meeting with the Borough Leads. A further five participants in group one were recruited from the two adjacent boroughs.

### 2.3.2 Group Two (Controls)

Women in the control group were accessed via the NHS Trust e-mail which asked women who met the stated criteria and who would be willing to complete a short questionnaire regarding their menstrual cycle to contact the author. Fifty six forms were sent out as a result of this and fifty usable forms were returned within the required time schedule.

Analysis of the trust e-mail address book revealed that 360 of the listed recipients were female. Human resources confirmed that the age of female employees within the trust was not skewed to either younger or older women and calculated that 50% of female staff would be within the requisite age range. The initial e-mail would, therefore, have reached approximately 180 women meeting the age criterion. The 56 returned forms (of which only 50 were completed correctly and used in the study) represented an initial response rate of 30%. It was recognised, however, that not all of the women in the requisite age range would have met the additional criterion for regular menstrual periods and non-consultation with a gynaecologist in the previous year. To ensure that this was reflected in the estimation of the response rate, the target group was set at 170. This means that the response rate represented 33% of the workforce meeting the criterion for inclusion in the study.

Attention was also given to the ethical considerations in recruiting to the control group. The ethics committee had indicated that as participation in the study was by means of self-selection, there were no outstanding issues of consent and that a separate consent form was not required. This was confirmed verbally in a telephone

conversation with the chair of the ethics committee. Issues of confidentiality were addressed by indicating that the MDQ could be printed and returned anonymously to the researcher. Attention was also given to the use of unsolicited e-mail, which may have caused annoyance to some women. To minimise this the initial e-mail asked women who were between the ages of 20-45 years of age and experiencing regular menstrual cycles and who would be prepared to participate in a research study by completing a brief questionnaire to contact the researcher for further information. In this way selection became an “opting in” process, the first step being the requesting of the questionnaire and the second being its completion.

#### 2.4 Sample Size

Sample size is recognised as an important factor in quantitative research as too small a sample may lead to an erroneous rejection of the experimental hypotheses (type II errors). Clark-Carter (1999) suggests three ways of estimating sample size prior to undertaking a study:-

- I. Use of previously published research.
- II. Calculating effect size from a pilot study.
- III. Reaching a decision prior to commencing the study on the required effect size.

There is no previous research using a self report measure regarding the menstrual cycle with women with learning disabilities and a sufficiently large pilot study was not undertaken. This means that sample size was calculated using (3) above. Use of

power analysis table (Clark-Carter, 1999) indicated that for a medium effect to be detected with a power of 0.8 then 50 participants in each group would be needed.

This was easily achieved with the control group. It only proved possible, however, to recruit 34 women with a learning disability to part one of the study. The impact of this on the results is considered in the discussion.

### **2.5 Measures : Moos Menstrual Distress Questionnaire**

The Moos Menstrual Distress Questionnaire (MDQ) (Moos, 1968; 1985) has been widely used in menstrual cycle research (Markum, 1976; Logue & Moos, 1986; Hart, Coleman & Russell, 1987; Corney & Stanton, 1991). The original scale (T form) involved daily ratings of symptoms using a 6 point Likert scale and is said to be “appropriate for repeated assessment of women’s reactions over time” (Moos, 1985). The scale itself was constructed by identifying most commonly reported menstrual symptoms by use of an open ended questionnaire and/or interview and from a review of prior research (Moos, 1968). Forty seven items were selected and women rated their experiences of these for each phase of their menstrual cycle. Subsequent factor analysis of ratings gave eight scales of ‘empirically related items’ (Appendix 6).

The C form of the MDQ was later adapted to allow for retrospective measurement of experiences of the most recent menstrual cycle using a four point scale (Logue & Moos, 1986 Appendix 7).

The aim of this study was to compare reported experiences between the two groups rather than to consider individual experiences over time. This means that the C form was considered the most appropriate measure available. Additional considerations in this decision were:

The scale could be completed in one session which minimised demands on the client group.

It is a relatively simple scale to complete and could be easily adapted for the client group.

#### 2.5.1 Reliability of the MDQ

The MDQ has been shown to be internally consistent and to have a high test-retest reliability irrespective of the menstrual state of the participant at the time of the study (Markum, 1976; Abplanalp, Donnelly & Rose, 1979). A comparison of concurrent and retrospective measures of cross cycle change using a modified MDQ also demonstrated a “good internal consistency and reliability” (Hart, Coleman & Russell, 1987). A comprehensive review of questionnaire methods of studying menstrual change concluded that, although the MDQ was subject to criticism, retrospective questionnaires can provide a reliable method of exploring experiences across the menstrual cycle (Richardson, 1990).

#### 2.5.2 Methodological Considerations of the use of MDQ with client group

The following points were considered when deciding on its use:-

#### 2.5.21 Understand of Rating Scale

There was concern as to whether or not the client group would understand the rating scale (a four point Likert scale from 'No change from normal' to 'Severe change'). After discussion with a Speech and Language Therapist a visual prompt consisting of lines of increasing length was devised to assist in rating change (Appendix 8).

#### 2.5.22 Understanding Concepts

The ability to understand the concepts 'before', 'during' and 'after' were also discussed with the Speech and Language Therapist. She suggested asking the participant to describe the following:-

- A. Something that had happened in the day preceding the meeting.
- B. Something that she planned to do during the day of the meeting.
- C. Something she planned to do in the next 24 hours following the meeting.

The Speech and Language Therapist's opinion was that, providing the responses given were verifiable, this would give a working definition of the client's ability to understand these concepts.

### 2.5.23 Provision of Assistance

Consideration was also given as to how much assistance to offer in the completion of the form: too much and the participant could have felt pressured to give the responses she thought were expected but too little may have led to more participants being excluded from the study simply because they were unable to read. It was decided that the researcher (or, if preferred someone of the woman's choice) would be present but would confine their assistance to reading (or clarifying) the words in the questionnaire and asking the woman to rate her experience with the aid of the prompt (Grove, Bunning, Porter & Olsson, 1999).

### 2.5.24 Validity of use of the MDQ with Women with Learning Disabilities

The MDQ has been widely used with different populations and has been shown to be relatively robust instrument which has a high correlation with prospective measurement of menstrual change (Moos, 1986; Hart, Coleman & Russell, 1987). It was recognised, however, that questionnaire had not been standardised women with learning disabilities and that this might qualify the results. Cook and Campell (1979) draw attention to the fact that few research designs are without flaws and that this particularly applies in undertaking research with clinical populations. Very few assessments and questionnaires have been standardised on people with learning disabilities (including many in use in clinical practice) and, theoretically, there was no evidence to suggest that women with a learning disability would differ from non-disabled women and require separate standardisation data. Nevertheless, as this

measure has not been standardised on a learning disabled population any differences found must be treated with caution as they may be artefacts of measurement.

The use of a mixed design in the methodology, therefore, was a means of minimising the limitations of using the MDQ alone. Additionally, considerable attention was given to the recruitment of the client group to ensure their understanding of the concepts utilised in the MDQ. It is possible, therefore, that the experiences of client group reported here may not be representative of the experiences of women with more moderate to severe learning disabilities and further research is needed in this area.

## **2.6 Pilot Study**

The C form of the MDQ was piloted on five women with a mild learning disability. The visual prompt was used to assist in identifying the differences between 'some change', 'moderate change' and 'severe change' (Appendix 8). All reported this being of value and it was therefore retained in the main study.

It was apparent that the factor scale six (Behaviour change) was not appropriate to the client group who have little control over such events in their lives. Additionally, they experienced difficulty in reporting on the control items (scale eight). As it is possible to use specific factor scales without necessarily affecting the reliability and as scale eight has been criticised as misleading and omitted from some studies (Clare, 1977; Moos, 1985) it was decided to omit scales six and eight from use in this study and two words were changed to make the form more accessible to a UK population (Appendix 9).



The feedback from the women was also positive which provided additional support for its use.

## **2.7 Procedure**

The letter sent to service providers included a copy of the questionnaire and the information sheet for participants (Appendices 9 & 10). The subsequent telephone call was aimed at ascertaining whether or not key staff would be prepared to identify potential participants and obtain consent to a meeting. Staff were provided with the inclusion criteria for the study and were asked to discuss with any women meeting that criteria whether or not they would be prepared to complete a questionnaire regarding their menstrual cycle. Staff were also asked to use a term that would be familiar to the participant and the majority identified the word 'periods.'

Names of potential participants were forwarded to the researcher who arranged an initial meeting with the woman. At this meeting the participant's ability to understand the relevant concepts was assessed. The participant was also able to say who they would like to assist in the completion of the questionnaire and a time agreed for completion.

Despite the attention given to identifying participants, six women experienced difficulty in comprehending the demands of the questionnaire. Time was spent with them talking about their periods but the questionnaire was not completed and they did not formally take part in the study.

## 2.8 Consent

It is a prerequisite that all psychological research should only be undertaken with the expressed consent of the participant (British Psychological Society; Code of Conduct, 1995). There are, however, specific considerations that have to be addressed when obtaining informed consent from people with a learning disability. The nature of their intellectual and social impairments means that the individual may not understand the nature of the research and this, combined with the known tendency to acquiesce, may influence their decision to participate in the research (Stalker, 1998; McCarthy, 1999).

Consent to participation in this study was in two parts. All participants completed a consent form to the completion of the questionnaire. Those participating in the qualitative component then had this explained in detail and signed the consent form required by the ethics committee (Appendices 10 & 11).

### 2.8.1 Consent to Completion of Questionnaire

The information sheet (Appendix 10) was discussed with the woman who was then asked the following questions:-

- I. What is the questionnaire about?
- II. How long will it take to complete?
- III. What will happen to it afterwards?

### 2.8.2 Consent to Interview

Obtaining consent to participation in the qualitative research followed the proposals made by Arscott, Dagnan & Kroese (1998). The research was described to the participants who were then asked the following questions:-

- I. What will we be talking about?
- II. How many times will we meet?
- III. What might be good about talking with me?
- IV. What might be difficult about talking with me?
- V. What can you do if you do not want to carry on talking with me?
- VI. Are you happy to take part in the interview?

In line with the findings of Arscott *et al.* (1998) all the participants were able to answer questions one and two with no difficulty; they knew that it was to talk about their menstrual cycle and that it would necessitate one meeting only. Good things about meeting were only indirectly related to the research and included comments such as “I want people to know how I feel”. All were able to say that they would be able to say when they had had enough and wanted to stop talking, although it has to be acknowledged that this may not have been so easy for them to do in practice. In arranging the interviews considerable time was taken to ensure that it was in a place and at a time convenient to the participant which may have contributed to the difficulty the participants experienced in identifying any negative consequences of participating. This may also be a reflection of the fact that there was only one meeting and all appeared to feel strongly about the subject.

## **2.9 Data Analysis**

The data obtained from both groups was analysed using Statistical Package for Social Scientists for Windows 1995 (SPSS). Both parametric and non parametric statistics were employed. The analysis sought to provide a comparison of the demographic data pertaining to the two groups in the study. The MDQ was analysed with regards to a comparison between the two groups for changes experienced across the cycle and an analysis of within group changes.

## **Part Two**

### **2.10 Qualitative Design**

This explored the experiences and understanding of the menstrual cycle in eleven women with a learning disability. A semi-structured interview schedule was used (Appendix 12) and the data analysed using qualitative methodology.

### **2.11 Selection of Participants**

Twelve women were identified as possible participants during the completion of the questionnaire. The aims of the interviews were explained to them. The women were asked at this stage if they had heard of the term “menstruation”. None knew the

word so a brief \*description was provided and the woman then asked what term she normally used to describe the event. This word was then used throughout the rest of the interview. Issues of confidentiality and anonymity were discussed at this stage and it was explained that they could withdraw at any time in the proceedings. The consent form was then signed. All agreed to take part but to ensure that they had time to reconsider their decision five working days were allowed to elapse before proceeding with the interview.

Although all twelve indicated their wish to participate one woman had to withdraw due to an unrelated illness. Eleven interviews were finally undertaken.

#### 2.11.1 Participants

The women had all participated in part one of the study and therefore met the inclusion criteria. An additional requirement for participation in part two was that they were not taking oral contraceptives. This was to facilitate comparison of themes. Details of the participants are shown in the results section.

\*The explanation varied slightly depending on the woman. They were asked if they experienced bleeding from their vagina (“down below” and gesture to between legs) approximately every 4-6 weeks and what did they call this. “Periods” was the most common term followed by “monthlies”.

## **2.12 Methodology**

For most of its history research in psychology has been influenced by the natural science approach to research. This approach is primarily concerned with 'standardisation, measurement and number' and in attempting to establish statistically significant associations between variables (Henwood & Pidgeon, 1992; Murray & Chamberlain, 1999).

During the last ten years or so increasing attention has been given to the value of the naturalistic paradigm and qualitative research methodologies within psychology. Such methodologies are of particular value when there is little previous research on a subject, and where the focus of investigation is on uncovering meaning and understanding the subjective experiences of the respondent (Smith, 1996a; Turpin, Barley, Beail, Scaife, Slade, Smith & Waisman, 1997). Barker, Pistrang & Elliot (1994) note that the additional advantages of qualitative research processes are that they:-

- I. allow for an in depth study of the individual.
- II. avoid oversimplification imposed by quantification.
- III. facilitate the generation of hypotheses.

## **2.13 Reliability and Validity**

The traditional methods of judging rigour in quantitative research have tended to concentrate on specific aspects of the methodology such as issues of reliability and

validity, replicability and the generalisability of the findings (Henwood & Pidgeon, 1992). This means that the traditional methods of evaluation do not apply to qualitative research where the emphasis of the enquiry is on meaning and personal experience and that alternative methods of establishing rigour need to be sought (Henwood & Pidgeon, 1992; 1995). The following have been proposed and are considered in relation to this study:-

#### 2.13.1 Independent Audit

If the research process is explicit and sufficient details provided so that it is accessible to others then it is possible to subject the findings to independent audit (Stiles, 1993). Here, two colleagues acted as auditors. Each read three randomly selected transcripts together with the initial notations, emergent themes and table of super-ordinate themes. The auditors were asked to follow the analytic process and comment as to whether or not the process was transparent. In all cases the auditors confirmed that a systematic process had been followed and that the final themes were grounded in the text.

#### 2.13.2 Replicability

The methodology, including data collection, interview schedule and subsequent analysis are presented in sufficient detail to allow others to replicate the work. To facilitate this process the interview schedule, annotated transcripts and table of superordinate themes are presented in Appendices 12-14.

### 2.13.3 Presentation of Evidence

Sufficient verbatim extracts from the transcripts are presented to allow the reader to make their own evaluation of the findings in line with the suggestions by Smith (1996b).

### 2.14 Interpretative Phenomenological Analysis

Interpretative phenomenological analysis (IPA) is a method of qualitative research that is being increasingly used in health psychology in exploring the experiences of a person in relation to their illness (Smith, 1996c; Osborn & Smith, 1998; Smith, Osborn & Jarman, 1999). As a process it has much in common with discourse analysis in the recognition it gives to the language used but differs from it in the attention it gives in attempting to understand the cognitive processes underpinning the individual account of their experiences. The researcher uses the analytic process in order to 'say something about that thinking' (Smith *et al*, 1999).

This study was concerned with understanding how women with learning disabilities understand and make sense of their experiences regarding the physical process of the menstrual cycle and particularly menstruation. IPA therefore appeared to be an appropriate method by which to analyse the participants transcripts.



## **2.15 Semi-Structured Interview**

A semi-structured interview schedule was deemed to be the most appropriate method of conducting this part of the study. The value of these schedules lies in their flexibility: efforts are made to establish rapport with the participants and the order of questions can be varied to allow for a more detailed exploration of an area of importance to the participant (Smith, 1996b). The ordering of the questions is of lesser importance than in a structured interview which means that the interviewer is able to explore issues which appear important to the respondent and to follow up areas of interest that arise through the interview (Smith, 1996b).

An additional consideration in deciding to use a semi-structured interview was to meet the specific needs of the client group: a degree of structure is usually necessary to facilitate discussion in people who may have difficulties in verbal communication (McCarthy, 1998b). Unstructured interviews can be particularly difficult for people with learning disabilities who are not used to speaking freely and who tend to respond to questions with relatively short answers (Booth & Booth, 1994; McCarthy, 1998b).

### **2.15.1 Interview Schedule**

The interview schedule was constructed following the guidelines given by Smith (1996c) (Appendix 12) and with a view to addressing the areas encompassed in the research questions. Questions were neutral and due care was given to avoid, where possible, the use of questions that would lead to 'Yes' or 'No' responses. The interview attempted to address the concerns of the women as they arose, using the

interview schedule as a prompt when necessary. Discussion of the following areas were, however, included, in all interviews.

**Section One. Factual Information.** This included detail such as age at menarche, length of cycle, length of menstrual bleed and understanding of the function of the menstrual cycle.

**Section Two. Current Experiences of Menstruation.** This aimed to explore any areas that were of concern to the woman regarding menstruation, including aspects of menstrual management and coping strategies. It included access to information and the availability or otherwise of help should this be required.

**Section Three. Emotional Response to Menstruation.** This section discussed the feelings the participants had regarding menstruation and whether or not there were any positive or negative features associated with it. It also attempted to explore the woman's feelings at the onset of the menarche.

**Section Four. Association with Sexuality and Fertility.** This was concerned with exploring how the participant viewed menstruation in relation to sexuality and also pregnancy. Both their understanding and feelings were considered.

**Section Five. Closure.** The participants were asked if they had had the opportunity to say all that they wanted to say. They were then asked if they had any further questions, if any unresolved concerns remained and, if so, whether or not they would like to see someone else to talk about this. One woman asked to be referred to a

community nurse and two more specifically requested that the interviewer write to their G.P. (Appendix 15).

All interviews were audiotaped with the consent of the participant. Each interview lasted between 30-60 minutes and before ending the interviewer explicitly enquired as to whether or not the respondent had anything more that they would like to add.

## **2.16 Data Management**

The interviews were transcribed verbatim and analysed using Interpretative Phenomenological Analysis. Each transcript was then read repeatedly so that a general sense of the participants' accounts was obtained. The audiotapes were also listened to in order to obtain any areas of particular emphasis given by the participant. The analysis then followed the process described by Smith, Jarman & Osborn (1999). When reading the transcripts points of interest were noted in the left hand margin; the scripts were then re-read and emergent themes noted in the right hand margin (an example of an annotated transcript is shown in Appendix 13).

IPA specifically acknowledges that final themes emerge as an interaction between the account given by the individual and the interpretations of these by the researcher. Accordingly, themes emergent from the first transcript were used as a basis to the analysis of the subsequent transcripts. Some themes were later discarded as other themes began to emerge and earlier transcripts were re-read for evidence of these themes which emerged from later transcripts. Finally, the preliminary themes

were examined for shared, superordinate themes which were then developed into a master list (Appendix 14).

## **CHAPTER 3 : RESULTS**

### **3.1 Part One: Quantitative Results**

The analysis of the data was based on 84 completed questionnaires, 34 in group one (client group) and 50 in group two (controls).

### **3.2 Comparison of Groups**

#### **3.2.1 Age, age at menarche, cycle length and menstrual flow**

Consideration was given as to the use of parametric or non-parametric statistics. A key criterion for the use of parametric statistics is that the data should follow a normal distribution. A further criterion is that that data should be interval (Clark Carter, 1999). Histograms were used to ascertain the distribution of data and in all cases it appeared to follow a normal distribution (Appendix 16).

Levene's test for homogeneity of variance was used to establish the validity of the use of the parametric t-test (Kinnear & Gray, 1997) with regards to the following:-

- A. Current age
- B. Age at menarche
- C. Length of menstrual cycle
- D. Number of days of menstrual flow

In each case the obtained f value (Levene's test) was not significant and the variances were therefore assumed to be equal (Table one). The independent t test was then used to compare means and their results shown in table two.

Table one : Levene's test for equality of variances: Age, menarche, length of cycle and menstrual flow

Variable	f value	Sig
Age	0.007	0.931
Age at menarche	1.232	0.271
Length of cycle	0.967	0.329
Menstrual flow	1.782	0.186

Table two : Results of t tests for age, age at menarche, length of cycle and menstrual flow

Variable	Group 1 (Clients) Mean & SD	Group 2 (Controls) Mean & SD	Mean Difference	t-Value	df	Probability
Age	33.44 yrs (7.20 yrs)	32.02 yrs (6.98 yrs)	1.42 yrs	.514	82	0.369
Age at Menarche	13.20 yrs (2.10 yrs)	12.98 yrs (1.66 yrs)	.22 yrs	.514	75	0.609
Length of Cycle	26.13 days (4.04 days)	27.76 days (4.25days)	-1.63	-1.54	71	0.127
Days of Menstrual Flow	4.03 days (1.64 days)	4.78 days (1.31 days)	-.75 days	-2.521	82	0.023*

\* Denotes a significant result

The differences between the groups in terms of age, age at menarche and length of cycle were not significant. The difference in number of days of menstrual flow was significant and this will be considered in the discussion.

### 3.2.2 Place of Residence

Table three gives the places of residence for both groups.

Table three : Pattern of living arrangements

<b>Group</b>	<b>Own</b>	<b>Parents</b>	<b>Partner</b>	<b>Residential</b>	<b>Other</b>
Clients	4 (11%)	8 (23.5%)	2 (5.9%)	11 (32.4%)	9 (26.5%)
Control	7 (14%)	2 (4%)	32 (64%)	0	9 (18%)

There are obvious differences between the groups: 64% of non-disabled women live with a partner compared with 2% of women in the client group. None lived in a residential setting whereas 32% of the client group were in such a placement.

### 3.2.3 Recognition of term “pre-menstrual syndrome”

The questionnaire asked the participants in both groups whether or not they had heard of the term “pre-menstrual syndrome”. All participants in the control group had heard of the term compared with only one woman in the client group. The implications of this will be considered in the discussion.

## 3.3 Analysis of MDQ Responses

As the data was ordinal, a non-parametric statistic was used in the analysis.

3.3.1 Research Question one: Do women with a Learning Disability report the same symptoms as non-learning disabled women with regards to changes within the menstrual cycle?

The Mann Whitney U test was used to analyse the differences between the groups with regards to changes experienced across the menstrual cycle. No direction of difference was hypothesised and the results are summarised in table four.

Table four : Results of Mann Whitney U test for between group symptoms change across the menstrual cycle

Variable	Group 1 Mean Rank	Group 2 Mean Rank	U	Z	Probability
Pre-menstrual symptoms	31.88	49.72	489.000	-3.291	.001*
Menstrual symptoms	45.75	40.29	739.500	-1.007	.314
Post-menstrual symptoms	44.01	41.47	798.500	-0.484	.629

\*Denotes a significant result

- I. The difference in the reporting of pre-menstrual changes was highly statistically significant ( $U=489.000$ ,  $Z=-3.291$ ,  $p<0.001$ ). The mean rank for the two groups indicate that the client group reported fewer changes occurring in the pre-menstrual phase than the control group.
- II. The client group reported more symptoms than the control group during menstruation, although the difference was not statistically significant ( $U=739.500$ ,  $Z=1.007$ ,  $p>0.314$ ).
- III. The client group reported more post-menstrual symptoms but this was not significant.



3.3.2 Research Question two: Do women with Learning Disabilities report a significant difference in changes occurring across the phases of the menstrual cycle and do these differ from the changes reported by the control group?

The analysis was within subjects. The data was ordinal in form and there were more than two conditions to the independent variable. The conditions for a Friedman's two-way analysis of variance were therefore fulfilled, and the results are shown in table five.

Table five : Results of Friedman's two-way ANOVA within group change across the menstrual cycle

	Mean Rank			Chi square	df	Probability
	Pre-menstrual	Menstrual	Post-menstrual			
Group 1	2.15	2.76	1.09	51.138	2	0.001*
Group 2	2.69	2.26	1.05	72.673	2	0.001*

\*Denotes significant results

- I. There was a significant difference in the reporting of symptoms across the cycle in women with learning disabilities ( $\chi^2$  51.138, 2 df,  $p < 0.001$ ).
- II. The control group also showed a significant difference in the reporting of symptoms across the cycle ( $\chi^2$  72.673, 2 df,  $p < 0.001$ ).
- III. Both groups reported fewest symptoms in the post-menstrual phase (mean rank for client group 1.09 compared with 1.05 for the control group).
- IV. The client group experience more symptoms during menstruation than in the pre-menstrual phase.
- V. The control group demonstrated a reverse pattern with more symptoms being reported in the pre-menstrual phase than during menstruation.

### 3.3.3 Comparison of means of the factor scales of the MDQ

Table six shows the means for the factor scales for the client group, the controls and the normative data reported by Moos (1968; 1986).

Table six : Means and SD of MDQ form C for each phase of most recent cycle

Factor Scale		Client		Control		US Sample	
		Mean	SD	Mean	SD	Mean	SD
Pain	Before	5.50	4.91	<b>7.52</b>	5.26	4.03	2.65
	During	<b>9.32</b>	6.34	7.88	4.53	5.22	2.69
	After	1.00	2.00	0.67	1.24	<b>1.80</b>	1.80
Water Retention	Before	2.35	2.69	<b>6.42</b>	3.72	3.25	1.81
	During	<b>5.60</b>	3.39	4.40	3.57	3.11	1.69
	After	2.94	0.17	0.66	1.46	1.02	1.00
Autonomic Reaction	Before	1.73	2.27	<b>2.70</b>	2.81	0.78	1.14
	During	<b>3.64</b>	3.64	2.60	3.18	1.08	1.38
	After	0.14	0.43	<b>0.38</b>	0.94	0.35	0.80
Negative Affect	Before	8.61	7.45	<b>12.46</b>	7.86	6.40	4.09
	During	<b>11.75</b>	8.08	7.80	7.24	6.17	3.72
	After	1.08	2.03	1.48	4.35	<b>2.99</b>	2.60
Impaired Concn.	Before	4.47	4.74	<b>7.76</b>	6.84	6.40	4.09
	During	<b>7.23</b>	6.84	5.38	5.45	2.57	2.33
	After	1.05	2.56	0.66	1.36	<b>1.46</b>	2.09
Arousal	Before	1.24	1.81	3.06	3.19	<b>3.77</b>	2.47
	During	1.38	2.21	2.30	2.74	<b>3.42</b>	2.16
	After	1.52	2.31	2.14	3.15	<b>3.77</b>	2.47

Figures in bold type denote the highest score in each phase of the cycle.

### Summary of Findings

- I. The client group achieved the highest score on five out of the six scales with regards to symptoms occurring during the menstrual cycle. This was particularly marked for the scales measuring pain, impaired concentration and water retention.

- II. The control group achieved the highest score in five out of six categories with regards to pre-menstrual symptoms. This was particularly apparent for the scales measuring water retention and negative affect.
- III. The mean for each scale was higher in both the client and control groups than the USA sample with the exception of the scale measuring arousal. This was higher in the USA sample in all phases of the cycle.

### **3.4 Part Two: Qualitative Analysis**

This will be reported in two parts.

3.5 Details of the participants

3.6 Analysis of the transcripts using IPA

### **3.5 Details of participants**

\*Table seven : Details of participants

Participants	Age	Placement	Support	Partner	Children
1. "Laura"	40	Small catholic residential home	Staff in home	Boyfriend	No
2. "Rachel"	24	As above	As above	Boyfriend	No
3. "Moira"	42	Own home	Mencap + Community Nurse	Boyfriend	1 at home 1 adopted
4. "Lucy"	20	Residential home for women	Staff in home	No	No
5. "Lois"	36	Family home	Sister + Mencap	No	2 at home
6. "Claire"	32	Family home	Mother	No	No
7. "Carrie"	28	Family placement	Carer	Boyfriend	No
8. "Kate"	36	As above	As above	No	No
9. "Sara"	34	Housing association flat	Mencap Community Nurse	Husband	No
10. "Jodie"	44	Own flat	Mencap	No	No
11. "Marie"	30	Own flat	Mencap	No	2 at home + twins adopted

\*All names are anonymous to protect confidentiality.

The above table gives details of the participants, all of whom met the criteria for Adult Learning Disability Service within the funding borough\*. The five women who lived on their own all received support from a domiciliary outreach worked funded by social services. This support was not less than weekly and for one participant (Marie) it was on a daily basis.

The participants were asked where they would like the interview to take place and all chose their own home. Claire asked if her mother could be present and this was agreed. Marie's support worker was in the home but looked after Marie's child in another room.

Three women had had children and of these two (Moirra and Marie) had had the experience of three of their children being adopted against their wishes. Both women, however, also had children under the age of ten years living with them and were receiving additional help in their care.

\*(IQ<69 together with a marked impairment in functional skills, both of which were developmental in origin).

### **3.6 Transcripts of Interviews**

The transcripts were analysed according to the way described in the methodology. The following master themes were identified and are presented with their emergent themes. Examples from the transcripts together with the number of women contributing to each sub theme are shown in Appendices 13 & 14.

***Theme one.    Uncertainty and confusion***

- Terminology used
- Preparedness for menarche
- Access to information

***Theme two.    Menstruation as a debilitating condition***

- Pain
- Blood loss
- Mood changes
- Biomedical discourse

***Theme three.    Impact on lives***

- Menstrual management
- Coping strategies
- Support needs
- Restriction of activities
- Seeking help

***Theme four.    Negative attitudes to menstruation***

- Response to menarche
- Current attitudes
- Influence of others on attitudes

***Theme five. Impact on Identity***

- Identification with other women
- Adult status
- Social comparisons
- Staff control
- Need for privacy

***Theme six. Relation to Sexuality***

- Uncertainty
- Sexual identity

3.6.1 Theme One. Uncertainty and Confusion

Despite the fact that all the participants in this study would be considered as having a mild learning disability and that some could read, none knew the meaning of the term menstruation with “*No, never, what’s that?*” (Rachel) being a typical response. The participants were asked what words they would normally use and which they would feel most comfortable with using in the interview. “*It’s a period*” (n=8) was the most common response followed by “*It’s your monthlies*” (n=3).

During the interview it became apparent that none of the participants were familiar with any of the words used with regards to changes in the menstrual cycle. The response to whether or not they had heard of pre-menstrual tension (PMT) ranged from a “*I’ve never heard of that*” (Marie) to “*I’m only 37; you get that in your 40s,*

*don't you?"* (Lois) and a vehement *"I've never had any of that, never"* (Jodie). The same applied to the menopause:

*"I asked my sisters, 'what are these menopause's?' and they said 'it's just part of your nature, your menopause's are in your body'. Well, I cottoned on then and felt better"* (Jodie)

When asked about the onset of menstruation none of the participants had felt prepared for the menarche: *"I was in the kitchen cooking and I said to my mum, I must have cut myself... there... but she said 'no, it's your periods"* (Rachel). Explanations had not been forthcoming other than to provide a label (*period* or *monthly*) which had not remitted over time. This meant that all were still profoundly uncertain and confused as to the processes and purpose of menstruation. Comments varied from a simple *"don't know what they are for"* (Claire) to the more confused explanation provide by Moira:

*"The blood circulates in your stomach and it swells up and you have belly aches and cramps and that is how your period starts. When my sisters told me where the blood would come out I went 'ooh, blood, blood, blood"*

Their perception of the information given at the time was that it had been limited and that information provided at school had either been non-existent (*"They didn't talk about it at school"* Claire and Laura) or limited to *"condoms and things like that"*

(Marie). None appeared to be sufficiently confident to request more information from carers, family or support staff.

There was a desire for more information: *"I want to know more about them, what can be done"* (Rachel) and *"We should have more information and support"* (Lucy) but uncertainty as to how this could be accessed.

### 3.6.2 Theme Two. Menstruation as a Debilitating Condition

As the participants described their experiences it was clear that the majority (n=10) experienced what they described as *'excessive pain'* with menstruation. Lois spoke for the majority when she said that *"the pain is everywhere in your body"* whilst Sara *"could not move because of the pain"*. The pain as seen as an overwhelming factor in their lives which could be neither controlled or ignored: Clare described it thus:

*"It feels like the bones in me are pulling out and I have to have a hot water bottle all the time and it hurts"*

The description they gave of the pain was something more than discomfort; it was, as described by Moira, *"agony"*. At least eight of the participants described additional somatic changes which had a major impact on their lives. These ranged from being *"hot and sick"* (Kate) to *"being as cold as ice"* (Moira) and to *"having blackouts"* (Jodie).



In addition to the pain nine of the women also complained of menorrhagia (heavy menstrual blood loss).

*“I have to change big pads six or seven times a night because I soak through them. My mum was like that. I soak through onto the bed” (Carrie).*

Clare also said that there was often *“blood all in the bed”* and Laura had to always *“use two pads”* to prevent blood leaking through onto her clothing.

It is not clear from these accounts whether or not the women did, in fact, experience heavier and more painful menstruation's than would be anticipated from a non-disabled group. Both pain and menorrhagia are subjective experiences and are a consequence of a multiplicity of factors including knowledge, expectations and controls (Bevis, 1993). It is inescapable, however, that for the participants menstruation was construed as a debilitating condition which, literally, made them *“ill”* (Jodie). Perhaps it is therefore not surprising that the combination of pain and heavy blood loss also had a significant impact on their mood. Sara said that *“I cry and am always in a bad mood”* whilst Laura acknowledged that *“I’m moody and snap at people”*. For these women it was clear that the change in mood accompanied the onset of menstruation and was not a feature of the pre-menstrual period.

### 3.6.3 Theme Three: Impact on Lives

Perhaps unsurprisingly, in view of the reported debilitating effects, menstruation had a significant impact on the lives of nearly all the women. The management of the menstrual flow itself caused considerable problems and was remarked on spontaneously by the majority:

*"I tried Tampax once but I don't like them... I mean they are too dangerous. There is a special way you have to use them... I prefer to use ordinary towels, they're easier"* (Carrie)

This theme of Tampax (or any other internal menstrual protection) being somehow difficult or dangerous was echoed by a number of the participants including Kate who said *"I can't use Tampax..... they're too uncomfortable"* and Moira *"no, not them tampons... no never..."*. This unwillingness to consider the use of Tampax or their equivalents appeared more than just a reluctance to switch from a tried and tested, familiar product and may be associated with their lack of knowledge and lack of ease with their bodies: No participant, for example, mentioned the word vagina; two made references to *'down there'* and a third to *'underneath'* whilst the others avoided any direct reference to their genitals.

This is not to imply that the use of sanitary pads was any easier. Those in residential homes fared worse with having to ask staff either for pads or the money with which to purchase sanitary products. Rachel was dependent on others to buy them for her (for reasons which never became clear as she was able to travel to college

independently and also to shop on her own). Consequently, other people were more likely to influence or control the type of protection used, which was not without its difficulty:

*"I had to say to my mum, 'stop buying me the little ones, they're no good. I can't cope with the little ones any more I need the big ones, the long ones, not panty liners. I mean I just leaked everywhere with those" (Rachel)*

The problem of leakage was common to a number of the participants and appeared in excess of what would normally be expected. Carrie described having to take *"protective clothing, spare trousers and knickers, that sort of thing"* when she went out whilst Kate described difficulties at night:

*"I leak a lot and at night I have to get up and change the sheets so I can wash it out ... and it might leak in the day as well so I have to take things to work, clothes and that"*

The frequent use of the words *leak* and *flood* conveyed the impression of every menstrual bleed being a force that threatened to overwhelm them if sufficient defences in the form of extra clothes, old sheets and towels weren't employed. Yet in other ways the participants showed themselves to be remarkably up to date with recent changes in sanitary pads and at least eight of them made references to adverts that they had seen in magazines or on the television:

*"I use them towels, proper towels like they advertise on telly where you don't feel the wet going through. Well I use them 'cos they are better"* (Lois)

and Laura who said *"I buy them new ones called 'Always', the ones with wings"*. These accounts indicate that the women in the study were not simply set in their ways and passively accepting difficulties in menstrual management but were responsive to advertising aimed at women with whom they could identify. Similarly nearly all recognised that menstruation need not necessarily lead to any restriction in activities; four mentioned that they could not go swimming when menstruating (presumably because of not using tampons), Claire stated that she could not *"use my exercise bike because I get pins and needles"* but none said that they could not bath or wash their hair... myths prevalent just over a generation ago (Kissling, 1996).

Yet when it came to considering coping strategies the most commonly mentioned was the use of analgesia such as panadol or anadin. For Lois *"a hot bubble bath"* helped whilst Moira found it useful to *"drink hot tea and drinking chocolate"*. Others found these less useful: *"I have hot water bottle but that doesn't work and a hot bath and that doesn't work"* (Rachel). When consulted, general practitioners had not been found to be helpful and of those who had consulted their GP, none had been offered the opportunity to meet with a practice nurse or attend a well-woman clinic.

*"They use words you don't understand... because I go to the doctors on my own..... and they sometimes talk too fast" (Kate).*

whilst Sarah, who had also consulted her GP, had had a similar experience:

*"Doctors aren't always sympathetic. They need more training. Every time I go and see him he goes on about my weight. He nags me so I'm not that keen on him"*

Claire also found professionals unapproachable and stated that *"my doctor doesn't talk to me. I wish he would"*. This was later supported by Claire's mother who confirmed that as Claire was unable to attend appointments unaccompanied it was too easy for the Doctor to ignore Claire and speak to her mother. Her mother added that she always pointed out to professionals that her daughter was able to speak and invariably knew what she wanted.

There was a degree to which the participants appeared isolated in the difficulties they were experiencing. There is no doubt that they were able to, and did, identify with women portrayed in adverts in the media and were happy to try out new products. This did not extend to tampons which were rejected by all, possibly because of lack of knowledge and familiarity with their body.

#### 3.6.4 Theme Four. Negative Attitudes to Menstruation

This theme underpinned a number of the other themes yet there were sufficient references to the participants' attitude to menstruation and how these had been shaped to consider it as an independent theme. Attitudes were predominantly negative and appeared to have been shaped by their reaction to the menarche which was still recalled by Jodie as a traumatic event.

*"When I first started to bleed with my periods I was blacking out so much that the doctor put me on Largactil to calm me down. As the years have passed they've stopped, the blackouts, but I was scared when I started my periods"*

It was as if early experiences had shaped their perceptions of menstruation and that later experiences, rather than allowing for a reconstruction of the menstrual cycle, had served only to confirm these experiences. Those living in residential homes experienced that additional problem of having to cope with care staff who demanded to know the details of menstruation:

*"they say, when you get your period tell me so I can write it down....having to tell them when your period starts, that's not nice.." (Lucy).*

The conflict between menstruation as a public event and yet also a private one was particularly apparent for both Rachel and Lucy who were the youngest women in the study and both also lived in residential services. Lucy expressed anger and frustration at the lack of control which she experienced in the face of an apparently powerful staff group

*“They say they have to know and I keep asking them ‘Why do you have to know, why do you have to write it down?’ But they don’t answer. They have a book for everything... so it’s all public”*

Rachel was more explicit in her views with regard to control and power:

*“I hate most having to tell the staff. I can hear them in the office, all talk, talk, talk. I mean they are controlling us. They treat me like a baby. I wish I wasn’t here at all”.*

This was an area of conflict for many of the participants, not just Lucy and Rachel. All those living in a residential service or with carers ‘had’ to report the onset of menstruation to someone else which reinforced feeling of being dependent on others and not in control of their own lives.

Carrie noted that:

*"I write them down for \*M... and then she writes them in  
he red file and then \*D...checks them when she does her  
home visit. She keeps check on them and makes sure  
they're regular every month".*

None of the women had been given what they considered to be a satisfactory reason for this degree of monitoring and it was hard not to form the impression that the staff were also, in a crude way, controlling or monitoring any possible sexual behaviour. Menstruation was also recognised to be a private event and in this the participants appeared to be responding to the covert message given to women generally that menstruation is not something to be talked about. Lois (who lived with her sister) remarked that *"I don't talk about them to my sister... I don't talk about them to anyone"* which perhaps sums up the attitudes of all the participants; that they would prefer not discuss their menstrual cycle with anyone, but particularly not with staff members.

None but Marie could see anything good about menstruation (and her comment was restricted to saying that *"they are all right I suppose"*) and were generally vociferous in wanting them to stop. Indeed, Sara spoke for the majority when she said:

*"There's nothing good about them, nothing at all. I  
suffered when I was younger and they are not good now. I  
just want them to stop".*

\*M. was the carer with whom Carrie lived and D was her care co-ordinator



### 3.6.5 Theme Five. Impact on Identity

It was apparent that the participant's had a strong sense of their identity as a woman and also that they identified with other women. For Carrie this was in relation to her care co-ordinator "*She's my age, I can relate to her*" whilst for others it was in relation to women in general rather than a specific individual "*it's something us women have to go through*" (Claire). At times this reflected their negative perception of menstruation as "*we just have to suffer them*" (Kate) and "*sometimes wish I'd been a man, they don't have to have periods*" (Lucy). Lois also revealed ambivalence when she talked about her dislike of menstruation and the difficulties she experienced. It was apparent that this was a way in which she could position herself as a woman and identify with the researcher as a woman.

*"I just think more should be done for us women... what we have to go through, it's not nice, not nice at all and something should be done for us".*

and later in the interview she returned to this when she said "*it's something us women have to put up with*".

For some participants the menarche and menstruation was seen as conferring adult status "*it made me feel like an adult and that was good*" (Moirá) "*it's a ladies thing, you're getting to be a woman*" (Jodie) and "*It's part of growing up*" (Sara). Comparisons with other women were sometimes used to illustrate a point:

*“my sisters have it easier than me and what puzzles me is that I have had periods and they don’t, it’s only me in the family that has it bad” (Moir).*

Contained within this was also uncertainty as to why they suffered more than their friends or sisters *“I don’t know why but my sisters can use Tampax but I can’t”* (Jodie).

At no time did any of the participants make any reference to their learning disability and it was noticeable that they positioned themselves as women first. This was easier to achieve for those living in relatively independent placements or independently but much harder to achieve for those in residential services who were very aware of the difference between being a staff member and a resident. Lucy was the most outspoken.

*“When they talk about us, our periods, they should do it with us ... I mean we don’t ask them when their periods coming... but they don’t, they just go upstairs to the office and talk amongst themselves”*

This seemed to be dilemma for at least three of the participants; that although they clearly saw themselves to be both an adult and a woman this did not always appear to be recognised or accepted by others. This left them searching for a way to effectively attain the recognition that they felt they deserved.

### 3.6.6 Theme Six. Relation to Sexuality

There was considerable confusion and uncertainty on the part of all the participants with regards to sexuality. This was particularly noticeable regarding the role of the menstrual cycle in relation to fertility, so that the theme is characterised by to the extent that it is a theme characterised by anxiety and uncertainty. None of the participants made spontaneous references to sexuality; in all interviews comments arose from prompt questions.

All of the participants knew that that menstruation had some relationship with becoming pregnant but expressed no knowledge of ovulation and when conception may be expected to occur. Moira (who had had three children) said that *"I know we have periods because of babies... but, well, I'm not sure how"* whilst for Lois (who also had children) her knowledge was sketchy and inaccurate:

*"It's the change, isn't it? If you don't have periods it can stop you getting pregnant but then I got pregnant and I wasn't even on my monthly so I don't know... I didn't know I was pregnant for a long time"*

For Jodie the whole subject was wrought with uncertainty and she appeared distressed when talking about it:

*"Well, let's say I didn't have a period my hormones would be wanting me to have children but I don't know how you*

*get pregnant. There's a link between getting pregnant and periods but I don't know what it is. Talking for me is better than having intercourse because I wouldn't know if I was going to be scared, frightened or upset so I've never had intercourse"*

She had resolved this by allowing others to make the decision for her.

*"There's no need for me to have intercourse, the doctor said so, so I don't know about periods and I don't know what they are for"*

Although less explicit others also echoed the theme that as they were not sexually active then there was no need for them to concern themselves with menstruation.

*"I don't know how periods link with becoming pregnant... I know you get pregnant when the time's right and it's not the right time for me" (Carrie).*

and

*"Periods are to stop you getting pregnant, that's what I was taught, you get pregnant when you have a boyfriend and sleep with him.. I've heard about that, but I don't have a boyfriend so that doesn't affect me.." (Kate).*

The focus of sexuality was equated with heterosexual, penetrative sex “*when a fellow does what he does*” (Lois) and “*when a man puts his penis inside you*” (Laura). Rachel said that “*You can’t have sex when you’ve got a period*”. A number echoed Kate’s comment above, that if they did not have a boyfriend or were not having full intercourse then they need not concern themselves with the link between sexuality and the menstrual cycle. Even though three of the women had had children and a number described having “boyfriends” there was no strong sense of them having a sexual identity or of being in control of their sexuality or aware of the reproductive processes.

## **CHAPTER FOUR: DISCUSSION**

The discussion will consider the following:-

- 4.1 The results of the quantitative data of the study.
- 4.2 The results of the qualitative data of the study.
- 4.3 Summary of quantitative and qualitative results.
- 4.4 Methodological considerations.
- 4.5 Clinical and service implications.
- 4.6 Future research.
- 4.7 Conclusion.

### **4.1 Discussion of the Quantitative Data**

#### **4.1.1 Menstrual facts: Age at menarche, cycle length and days of menstrual flow**

Previous research has found that girls with severe learning disabilities experienced the menarche some twenty one months later than the mean age for the general population (Culley, 1974; Evans & McKinlay, 1988). The results here, however, found that the client and control groups were matched for current mean age and mean age at menarche. The apparent difference may be a result of the different ways in which the data was collected. Both Culley (1974) and Evans & McKinlay (1988) accessed medical records to establish age at menarche and employed a definition of the menarche (“regular, established periods”) which excluded isolated occurrences of bleeding. In contrast, participants in this study were asked to give their

age at the onset of menstruation rather than the age at which they considered menstruation to be established.

When menstruation first occurs it is frequently irregular and may take some months before becoming established (Walker, 1997). It is therefore possible that the studies were, in fact, measuring different events; that women in both the client and control groups gave their age at their first menstrual bleed whereas the published research assessed the age by which menstruation was established. In this case an interval of some months would be expected (Evans & McKinlay, 1988).

An alternative explanation for the difference in findings, however, is that the published research relates to girls with severe learning disabilities whilst the participants in this study were considered to have a mild learning disability. It is therefore possible that girls with mild disabilities closely resemble the general population regarding age at menarche and that both differ from girls with severe learning disabilities who do, indeed, experience a later menarche.

Both client and control groups reported a mean cycle length close to twenty eight days whilst the number of days of menstrual loss was 4.03 days for the client group and 4.78 for the controls. Although the difference of 0.75 days was small it was, nevertheless, statistically significant. It is difficult to know whether this is a real difference or difference in the ways in which the two groups defined the start and end of menstruation. Ambiguities in this have been reported, particularly for women who have a gradual onset and/or who experience a day or two of "spotting" at the end of menstruation (McNeil, 1992). It was noted, for example, that when asked the number

of days of bleeding that the clients were less sure and more likely to give a general response (*"somewhere between three and five days"*) whereas the women in the control group tended to be more precise.

A cycle length of 28 days and a menstrual flow of four days both closely resemble the stereotype of a "normal" cycle. McNeil (1992) observed that the lack of variability in the reporting of such information has sometimes been questioned. She suggests that women use such terms as a form of shorthand to mean "normal for me" and only become concerned when there is significant deviation from their own "normal" cycle.

#### 4.1.2 Place of Residence

The two groups experienced very different patterns of living arrangements, which, to some extent, had been anticipated. The results, however, draw attention to how few women with learning disabilities have the opportunity to establish relationships, live in different partnerships or experience the range of accommodation available to non-disabled women (Brown, 1994).

#### 4.1.3 Knowledge of Terminology

PMS has been the focus of menstrual cycle research during the last 30 years and has received widespread reporting in the media (Chrysler & Levy, 1990) so it was not surprising to find that all of the control group had heard of PMS. In contrast only one of the client group knew the term. This may confer some advantage to the client



group as it has been suggested that women who are not familiar with the biomedical construction of PMS do not report experiencing it (Gottlieb, 1988). The converse position is that lack of knowledge of the term could serve to limit access to information available to non-disabled women.

#### **4.1.4 Analysis of the MDQ Responses**

##### **4.1.41 Research Question One: Do women with learning disabilities report the same changes across the menstrual cycle as non-disabled women?**

The results suggest that women with learning disabilities do differ from non-disabled women in the way they experience the menstrual cycle. The main finding was the highly significant statistical difference in the reporting of pre-menstrual change, the control group describing more symptoms than the client group. The reverse was found in the menstrual phase with the client group reporting the greater change, although the difference between the groups was not statistically significant.

The influence of cultural stereotypes on the reporting of PMS has been extensively documented in the literature and may have been a factor in the higher report of PMS symptoms in the control group (Parlee, 1973, 1974; Laws, Hey & Eagen, 1985; Ussher, 1999). This could also be taken as providing supporting evidence for the social construction of PMS (Rodin, 1992). Women with learning disabilities, who did not know the term, would be less subject to being influenced by the cultural connotations of the term (Gottlieb, 1988).

The result may also be a consequence of the control group. There are limitations in using a self selected control group as their willingness to participate in a study is possibly consequent on an interest in the subject not necessarily shared by all women; in other words they represent a distinct subgroup (Warner & Bancroft, 1990; Corney and Stanton, 1991). It could be hypothesised that those who responded to the email asking for participants were more likely to describe difficulties with their menstrual cycle than those who did not respond. This would then have contributed to the higher report of negative experiences in the client group. The same bias is unlikely to be applicable to the client group who were asked to participate in the study by key staff, mainly on their ability to meet the criteria for the study rather than on any assumed interest in the subject.

4.1.42 Research Question two. Do women with learning disabilities report significant difference in changes occurring across the different phases of the menstrual cycle and do these differ from those reported by non disabled women.

There was a significant difference in the symptoms experienced across the menstrual cycle in the women with learning disabilities. Symptoms were lowest in the post menstrual phase of the cycle, increased in the pre-menstrual phase and peaked during menstruation. The control group also reported a significant variation in cross cycle experiences but the trend differed from that of the client group: symptoms were also lowest in the post menstrual phase, then peaked in the pre-menstrual phase before gradually diminishing during menstruation.

Such variability is not necessarily surprising. The possible reasons for the higher reporting of pre-menstrual symptoms in the control group has already been discussed. However, although mood changes have been one of the most commonly reported experiences of PMS this is not always supported by empirical evidence (Ussher, 1992). Whilst several studies have, indeed, demonstrated an increase in negative mood premenstrually (Moos, 1968; Warner & Bancroft, 1990) others have found negative mood to peak during menstruation (Golub & Harrington, 1981) or for there to be no evidence of mood variations consistent with menstrual state (O'Neil, Lance & Freeman, 1984). Parlee (1973) points out that the discourse on PMS erroneously assumes that there is a stable base line by which change can be measured. The reality is that cyclical changes in mood and behaviour are common and that women do not have "times of normality (mid cycle) followed by times of illness (PMT and menstruation), when their hormones suddenly overcome them" (Laws, Hey & Eager, 1985). Equally it needs to be recognised that the focus on PMS has neglected consideration of the difficulties many women experience with menstruation. Choi & McKeown (1997) found that many non-disabled women dislike coping with menstruation, reporting management to be a "hassle".

The analysis of the interviews provides corroborative evidence that the women with learning disabilities report more symptoms during menstruation because they, like many non-disabled women, experience considerable difficulties with its management.

#### 4.1.43 MDQ: Comparison of means of clients, controls and USA normative group

Both the client and control groups in this study recorded mean scores above those of the USA sample for changes both before and during menstruation on five out of the six factor scales used in the questionnaire (table 6).

One possible explanation is that there was a difference in the constitution of the groups. The USA sample were a relatively homogenous group: they were young (mean age 25.2 years), well educated and married. In contrast there was greater heterogeneity in the control group. They were, on average, almost ten years older and living and/or working in an inner city, south London borough. The client group were also over 30 years of age, all had learning disabilities and would therefore have had very different educational and social history compared with the other groups. Women over the age of 30 have been shown to have a greater tendency to report negative symptoms both in the pre-menstrual and menstrual phases of the cycle compared with younger women (Rouse, 1978) which means that the differences in age between the USA sample and both the client and control group may have been a significant factor in the findings.

An alternative explanation is that the original work was undertaken over 35 years ago when the debate on PMS had only just started. During the intervening years there has been a dramatic increase in research into the menstrual cycle with the focus being on PMS (Chrysler & Levy, 1990). The women in the USA sample would not have been exposed to the negative stereotypes pertaining to the pre-menstrual phase of the cycle and, consequently, not subject to the influence of such reports (Gottlieb, 1988).

## **4.2 Discussion of Qualitative Results**

### **4.2.1 What characterises the experience of the menarche in women with learning disabilities?**

Within the general population 90% of women report having had information of the menarche prior to the onset of menstruation (Abrahams, Fraser, Gebski, Knight, Llewellyn-Jones, Mira & McNeil, 1985; Kissling, 1996). In contrast, the participants in this study recollected the onset of menstruation as a traumatic event for which they had been unprepared.

There are a number of possible reasons for the apparent lack of preparedness. It may be, of course, that information had been provided but that it had not been remembered or had been presented in a way that had meaning for the women and had therefore not been assimilated. Ussher (1989) observed that information regarding the menarche given to young girls frequently emphasises the biological processes but fails to address the social and sexual connotations of the event.

An alternative explanation is provided by consideration of the ways in which women in the general population acquire information regarding menstruation. The primary source is still the girl's mother with schools and friends providing secondary sources (Abrahams *et al.*, 1985; Kissling, 1996). When the experience of the participants in this study are considered it is apparent that these sources were not readily available to them. At least six of them had no or limited contact with their mothers in adolescence, schools were reported as focusing on the mechanics of

contraception and none appeared to have close friends at that time. Information that had been provided by family members appears to have been inaccurate ("*blood circulates in your stomach*") or factual only ("*It will happen every month*").

When the research evidence is considered in greater depth, however, it is evident that women with learning disabilities and non-disabled women do have common experiences. Both Abrahams *et al* (1985) and Kissling (1996) note that although adolescent girls had known of menstruation, the information given had been limited and some was identical to the information given to the participants in this study, that it was a monthly event and associated with adult status. Information emphasised the biological processes at the expense of the practical (what sort of pad to use; how often to change it) and the link between puberty and the development of sexuality was rarely acknowledged or explored (Abrahams *et al.*, 1985; Kissling, 1996). All girls said they would have welcomed more information and more opportunity to discuss their concerns and few considered that they had been well prepared for the menarche (Abrahams *et al.*, 1985).

#### 4.2.2 What do women with a learning disability know about the function of the menstrual cycle?

The normal functioning of the menstrual cycle is governed by a complex interaction of ovarian and pituitary hormones which serve to govern ovulation and hence the possibility of conception (Scambler & Scambler, 1993). The menstrual cycle is closely linked with sexuality which means it is not possible to consider it in purely

biological terms; the way in which its functioning is understood also has social and cultural explanations (Walker, 1999).

From analysis of the interviews it was apparent that the participants had no understanding of the function of the menstrual cycle other than to recognise it had an association with pregnancy. From a biological perspective none mentioned ovulation and even those who had had children did not know when conception was most likely to occur. In general people with learning disabilities have lower sexual knowledge than the general population (McCabe & Cummins, 1996) but even within that population knowledge may be limited: 40% of adolescent girls have been found not to know when ovulation occurs nor the critical time for conception (Abrahams *et al.*, 1985).

It is possibly because of its association with sexuality that so few of the participants had any understanding of the function of the menstrual cycle. Ussher (1989) has commented that many parents find it difficult to cope the onset of the menarche because it is outward evidence of impending sexual maturity; as a consequence they either seek to deny this by concentrating on purely biological explanations or become overly concerned with the possibility of pregnancy. Neither approach is likely to meet the needs of the adolescent girl (Ussher, 1989). It is likely that the reaction to the menarche in girls with a learning disability is even more complex: for too long people with learning disabilities have been construed as either being sexually profligate or an innocent to be protected (Clements *et al.*, 1995). This has led to the observation that "in every sphere of their sexual lives people with learning disabilities have a struggle" (Brown, 1994). It is therefore possible that the

lack of understanding of the menstrual cycle shown by the participants was not so much due to a lack of information (important though this is) as an absence of a clear sexual identity which would help integrate both biological and social meanings of the event.

#### 4.2.3 What are their current experiences of menstruation?

The participants experienced menstruation as a debilitating event, characterised by pain, heavy menstrual loss and considerable difficulty in managing the practical aspects of menstrual flow. To this extent they reflected the prevailing stereotype of menstruation as a “multi-symptom illness” characterised by a range of unpleasant physiological and psychological consequences (McFarland, Ross & DeCourville, 1989).

When the mainstream research is considered it is evident that the extent to which women experience pain with menstruation has been largely neglected (Walker, 1997). Evidence which has been published suggests that pain is a relatively common experience with 10-15% of women reporting “severe” cramps and a further 35% stating that they had “mild to moderate” pain on menstruation (Kessel & Coppen, 1953; Woods, Most & Dery, 1982). In this study pain was a powerful sub-theme for nine (82%) of the participants. It is not known why their experiences were more extreme than those reported by non-disabled women but the role of anxiety and knowledge on the perception of pain have been well documented (Morley, 1992; Bevis, 1993). The women had little knowledge of the biological processes involved in



the menstrual cycle and were vocal in their dislike of it, it is therefore not unreasonable to suggest that these factors contributed to their experience of pain.

Similar principles may have also been implicated in their description of menorrhagia. The upper limit of normal menstrual loss is given as 80ml (Bancroft, Williamson, Warner, Rennie & Smith, 1993) but many women have been shown to overestimate the amount lost, citing "litres" or "cupfuls" (Abrahams *et al.*, 1985). The majority of women who report menorrhagia have been shown to have a blood flow within the normal range (Bancroft *et al.*, 1993) which suggests that knowledge, expectations and management are important contributory factors. An important factor here is that not only did a significant number of women perceived their menstrual flow as excessive but also that they appeared to lack any help in addressing this problem.

In support of this, management of menstrual loss was also found to constitute a major problem. All of the participants used pads rather than tampons, their reasons being that tampons were somehow "difficult" or "dangerous" to use. Perhaps surprisingly, this is also reflected in the views of young adolescent girls. Although over 65% of young girls say they have tried tampons, in one study only 35% were using them on a regular basis (Abrahams *et al.*, 1985). The reasons for the non-use were similar to those given by the women with learning disabilities, that they were unsure of their anatomy, did not know how to insert one and feared that they would be uncomfortable to use (Abrahams *et al.*, 1985). Consideration of management tends only to appear in advertisements for sanitary products which stress the need to hide the fact that one is menstruating (Nicholson, 1995; Choi & McKewon, 1997). Given the

amount of distress surrounding management reported by all women then more open discussion on the subject would appear to be indicated.

#### 4.2.4 What are their attitudes to menstruation?

Research evidence suggests that attitudes to menstruation are mixed (Walker, 1997). Positive attitudes have been reported with statements such as “menstruation provides a reoccurring affirmation of womanhood” and “a means of keeping in touch with my body” being endorsed (Dunham, 1970; Brooks, Ruble & Clark, 1977). Others have reported that women do not consider menstruation to have any positive features (Choi & McKeown, 1997). The responses of the women in this study more closely reflected the findings of Choi and McKeown (1997): Menstruation was universally seen as a negative experience and source of considerable distress to the women. Only one participant (Marie) was neutral in her response (*they're all right, I suppose*); to the others there was nothing good about menstruation and they would be happy if they no longer had to menstruate.

A partial explanation for the absence of any positive attitudes may lie in the different methods of data collection: the attitudes and opinions expressed in this study were derived from qualitative interviews whereas the attitudes reported in the published works were obtained by the use of the Menstrual Attitude Questionnaire (MAQ) (Brooks, Gunn & Ruble, 1980). Although a prompt question had been “Is there anything good about having periods?” had been asked in the interviews, more specific probes had been avoided in order to minimise acquiescence and in order not to be too directive. It is possible that, if asked, statements such as “Menstruation

provides a way of keeping in touch with my body” (Item from MAQ) may have been endorsed.

Menstruation was, for those in residential and home placement settings, a public event with staff and carers requesting information about onset of menstrual period. The need to report the onset of menstruation to others was a source of conflict in that the women were aware of the prevailing view of menstruation as a private event, surrounded by taboos which emphasise the need for secrecy, avoidance of leakage and “mess” of any kind (Berg & Block Coutts, 1994). This raised issues of control for the women who, quite rightly, resented feeling like children in the face of a more powerful staff group. Staff motives were doubted and the impression given that staff were, in fact, monitoring sexual behaviour; that a record of a menstrual period meant that the woman was not pregnant.

#### 4.2.5 What is their understanding of menstruation with regards to sexuality?

Menstruation is inextricably linked with sexuality and the ability to reproduce (Ussher, 1989) yet for the women in this study they appeared to be two unrelated events. Their understanding of conception was limited (none, for example, mentioned ovulation) and even those women who had children were uncertain of how they had conceived. This is consistent with other findings pertaining to people with learning disabilities who have been shown to have lower levels of sexual knowledge than a comparative group (McCabe & Cummins, 1996).

It is perhaps not surprising that sex was viewed with considerable ambivalence. For those who had had children there had been additional difficulties with which to contend: the relationships with their child's father had not been sustained, there had been intervention by social services, court orders had been issued and finally, for two women, there had been the compulsory adoption of three of their children. For those living in residential services any sexual activity was the subject of monitoring and control by staff; of the five women living in residential settings only one was engaged in a sexual relationship and staff regulated it by determining when her partner could stay in her room. McCarthy (1993; 1999) has already written at length about the generally negative experiences of women with learning disabilities in relation to sexual activity and although the exploration was indirect in this study the findings are generally similar.

Brown (1994) has been critical of the support provided by services to people with learning disabilities regarding developing and sustaining sexual relationships. She argues that education provided does not give sufficient attention to the social issues involved and that a heterosexual preference has been assumed (Brown, 1994). This was certainly reflected in the experiences of the participants who appeared to have no strong sexual identity, displayed little understanding of their own sexual needs and had no appreciation of how these needs could be met.

#### **4.3 Summary of Discussion Pertaining to Quantitative and Qualitative Results**

The combined use of both quantitative and qualitative methods in a mixed design has proved valuable in describing the experiences of the menstrual cycle in women with

learning disabilities. The results of the analysis of the MDQ responses provide evidence for differences in the ways in which women with learning disabilities experience menstrual cycle change, a finding which is further supported by the analysis of the interviews. The accounts reveal a coherent picture of menstruation as a physically disabling condition which gives rise to considerable distress.

Previous research undertaken regarding the menstrual cycle in women with learning disabilities has concentrated on women with a severe learning disability and its association with other factors such as self injurious behaviour or difficulties in management (O'Dwyer & Friedman, 1995; Carlson & Wilson, 1996). This has contributed to the view that the menstrual cycle (and menstruation in particular) is a problem for women with learning disabilities. Solutions to the "problem" have been sought in the control or elimination of menstruation by medication, or in some cases, by surgery (Taylor & Carlson, 1993; Elkins, 1994; McCarthy, 1999).

The results also suggest that the focus on PMS in menstrual cycle research during the last 30 years is not directly applicable to women with learning disabilities and that there is a need to focus on the whole cycle rather than on one part of it. Evidence from research undertaken with non-disabled women, which also applied to the client group, suggests many are unprepared for the menarche and that the focus of education remains on a narrow, biological perspective which ignores the inextricable association with developing sexual maturity and sexual role. Equally, the difficulties that women with learning disabilities experienced with menstruation raises the question as to whether or not the concerns of non-disabled women have been appropriately

addressed by the focus on PMS in mainstream research and this would warrant further exploration.

It is evident that the participants experienced very real problems with menstruation and it would not be appropriate to interpret the difficulties experienced purely as a social construction. Neither, however, would it be appropriate to posit a purely biological explanation. The difficulties were not experienced in isolation but within the context of a system which tends to see the disability first and to ignore issues of gender, social and sexual identity for women with learning disabilities (Burns, 1993; Brown, 1994; Baum & Burns, 2000).

#### **4. 4 Methodological Considerations**

##### **4.4.1 The Menstrual Distress Questionnaire (MDQ)**

Retrospective questionnaires in general, and the Menstrual Distress Questionnaire (MDQ) in particular, have been subject to critical scrutiny (Richardson, 1990). Their reliance on the accuracy of memory for accessing data means that, should there be lapses in recall, they are open to being influenced by the prevailing negative stereotypes concerning the menstrual cycle (Parlee, 1973; Richardson, 1990). The MDQ contains a predominance of negative symptoms which increases the potential influence of cultural attitudes. This has led to the suggestion that daily ratings of mood and behaviour may provide a more accurate measure of menstrual variability (Richardson, 1990).

Despite these criticisms the MDQ has a number of advantages which justified its use here. The MDQ has been widely used, thus providing a body of knowledge with which to compare findings and not all findings have been critical (Markum, 1976). It is relatively straightforward to use and has been shown to be reliable both at test-retest and split-half conditions (Markum, 1976). It is also possible to adapt the scale to the particular focus of the research (Clare, 1977; Moos, 1985).

An additional advantage of its use was that the MDQ used retrospectively has been shown to have a high correlation with ratings derived from concurrent ratings using the same questionnaire (Hart, Coleman & Russell, 1987). This meant that it was possible to avoid the very real problems that would have been incurred with the client group in attempting to obtain data from daily ratings of mood and behaviour. Finally, using a questionnaire meant that a larger sample could be employed than would otherwise have been possible and that comparisons with a control group of non disabled women could be made.

#### 4.4.2. Sample Bias

Warner & Bancroft (1990) noted that women who respond to surveys may already have a particular interest in the subject and may not be representative of the general population. It is possible that those who chose to participate in the research (by replying to a trust email) experienced difficulties with their menstrual cycle or were predisposed to describing themselves as having PMS (Corney & Stanton, 1991). This would explain the high PMS rating on the questionnaire which may not be typical of all women. A more widely based community sample that was randomly selected,

although difficult to achieve, would limit any potential bias. The possibility of there being a similar bias in the client group this is less likely in that the women were asked if they would participate in the study on the basis of their ability to meet the inclusion criteria rather than on any presumed interest in the subject itself.

#### **4.5 Implications for Clinical Practice and Service Provision**

In learning disability services clients rarely self refer; other people, who may also make attributions regarding its cause, define their problem. This is particularly likely with women with a severe learning disability where problems such as self injurious behaviour are attributed to menstrual causes (Becker, 1999, personal communication). Where such clients are concerned it is important to ensure that an appropriate assessment is undertaken in order to support or exclude any presumed connection between behaviour and menstruation. Clinical work is often indirect, utilising a range of therapeutic approaches and undertaken at different levels within the service as the following suggestions indicate:

- I. The research has drawn attention to the limited knowledge women with learning disabilities appear to have regarding all aspects of the menstrual cycle. The provision of necessary information could be achieved by work with the individual, by working with staff groups or by facilitating groups regarding sex education and by taking a broader approach to work regarding personal relationships. A particular focus should be on menstrual management and in understanding the connection between menstruation and conception. Information needs to be presented in a way that is accessible to



women. This may mean utilising a range of teaching materials and ensuring that the women understand words used.

II. The absence of support networks was evident from the interviews. It is suggested that women with learning disabilities should have the opportunity to meet with other women with a view to sharing common experiences and gaining support regarding issues of sexual identity and gender related concerns (McCarthy, 1999). This again could be achieved by facilitating women's groups or providing supervision to those convening such groups.

III. Clinical psychologists occupy a role in service planning and development. The limited range of residential accommodation available to the participants was striking. In this study none of the women lived in mixed sex services but the residential home remained the main option for the client group. Attention needs to be given both to developing a more imaginative approach to accommodation as well as supporting women in developing both friendships and sexual relationships (Brown, 1994; Day & Harry, 1999; McCarthy, 1999).

IV. In line with government recommendations (Department of Health, 1998) professionals working in primary care settings need to be more aware of the needs of women with learning disabilities and this could be achieved by health psychologists working with practice nurses regarding health promotion. With one exception the women in this study had not found it easy to access help from their general practitioners or primary care settings, an issue which needs to be addressed.

Perhaps, however, the most important implication from the research is that psychologists working in learning disability services need to change their own practice to ensure that the gender specific concerns of women with learning disabilities are more effectively addressed.

#### **4.6 Recommendations for Future Research**

##### **Quantitative**

- I. To repeat the comparison of experiences between women with learning disabilities and non disabled women using a larger client group and a randomly selected control group. This would determine whether or not the findings reported here were peculiar to the participants or whether they apply to a wider group of women with learning disabilities. The hypothesis would be that non disabled women reported significantly more change in the pre-menstrual phase of the cycle whereas women with learning disabilities report significantly more change during menstruation.
- II. The changes women experience across their menstrual cycle could also be investigated further using a range of measures, which allowed for the reporting of positive as well as negative change. Again a larger client group would give greater confidence in the statistical results.
- III. The effectiveness of women's groups addressing sex education in its broadest sense need to be evaluated in order to ascertain the most effective way of providing women with learning disabilities with the information they say they need.

### Qualitative

The qualitative research has been particularly valuable in drawing attention to the way in which women with mild learning disabilities experience the menstrual cycle and could be extended. The following possibilities are suggested:-

- I. To explore in greater detail the understanding that women with learning disabilities have of PMS and its impact on their lives.
- II. To give consideration to their knowledge and subjective experiences of the connection between the menstrual cycle and sexuality with a particular focus on fertility.
- III. To identify their needs at the time of the menarche with a view to developing more effective communication regarding the event.
- IV. Finally, although there are considerably more difficulties in undertaking research with women whose learning disability would be considered severe it is important that consideration is given to their experiences and understanding of menstruation.

### 4.7 Conclusion

Research evidence has drawn attention to the importance of addressing gender specific issues in working with women with learning disabilities and the evidence reported here supports this position. The women participating in the research had limited knowledge of their bodies, a confused understanding of the menstrual cycle and experienced considerable difficulties with the management of menstruation.

Menstrual cycle research has been dominated during the last 30 years by the debate surrounding PMS. Whilst there was some evidence supporting the social construction of the syndrome it was also found that the participants in this study experienced real and considerable difficulties with menstruation itself. This suggests that the narrow focus on PMS fails to address the needs of all women and that the focus of research should be broadened to consider the whole of the cycle rather than its component parts. At least, the results suggest that the narrow focus on PMS in menstrual cycle research has not addressed the concerns of women themselves; that there is a need to consider the whole of the menstrual cycle rather than a specific phase within the cycle.

Finally the results illustrate that practices need to be re-evaluated at both an individual and service level to ensure that issues of gender continue to be addressed when working with women with learning disabilities.

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██████████ HOSPITAL TRUST

23 DEC 1999

Appendix 1

HOSPITAL RESEARCH ETHICS COMMITTEE

Medical Committee Office

Chairman -  
Administrator -

16/12/1999

Dr H Ditchfield  
Adult Learning Disabilities

Dear Dr Ditchfield

EC99/201     The experience of menstruation in women with a learning disability

Thank you for your correspondence dated 15.12.99 and for submitting a revised consent form requested by the Research Ethics Committee. This is satisfactory and I am happy for the study to commence.

Please note that this project carries a reference number, noted above, which must be quoted in any future correspondence.

The project number and the principal investigator must be clearly stated on the consent form. If approval is given to named investigators only, these names must also be stated on the form.

In the case of research on patients, a copy of the consent form must be placed in the patient's medical records, together with a note of the date of commencement of his/her participation in the research. A label must appear on the outside cover of the records when the patient is participating in the research.

The investigators must adhere to the published Guidelines of the Committee and provide the Chairman with annual progress reports and an end of study report. The research should start within 12 months of the date of approval.

The St Thomas' Hospital LREC is compliant with the ICH GCP requirements.

Yours sincerely

Dr

Chairman  
Research Ethics Committee

Dear Hedy,

Re: Proposed Research: The Experience of Menstruation in Women with a Learning Disability

Thank you for copying me details of your research project. I would assume that you would be looking for participants who may be using either residential, day or respite care services within Social Services. Please let me know if you want me to alert the Managers of these services in advance so that you have their full co-operation.

I look forward to hearing the outcome of this project.

Yours sincerely,



Joint Service Manager Learning Disabilities

Joint Services Manager

29/01/2000

Dear

**Re Research 'The Experience of Menstruation in Women with a Learning Disability'**

Thank you for your letter regarding the above in which you offer to alert managers of residential, day and respite services to the fact that I may be seeking participants from their services.

I have at last received ethical approval for the above research which means that I can now begin to collect data! I would therefore appreciate if you would alert the relevant managers to this study as I will, indeed, be needing participants from users of social services establishments.

Could I stress that participation will be entirely voluntary and for the majority will mean no more than the completion of a brief (and anonymous) questionnaire. Confidentiality will be protected throughout and the results will be used to inform local services in the needs of women.

Yours sincerely

Hedy Ditchfield  
Consultant Clinical Psychologist

Our Ref: HD/SE/Hedy/Dissertation

10<sup>th</sup> April 2000

Dear

**Re: Research: The Experiences of the Menstrual Cycle in Women with a Learning Disability**

As discussed in our telephone conversation on Friday, I am researching the above topic for my dissertation for a Doctorate in Clinical Psychology.

The research has approval (Ref. No. EC99/201) from the Ethics Committee at ..... Hospital and also has the support of ....., Joint Service Manager.

I am now seeking participants for the study.

1. A large number of women between the ages of 20-45 who are menstruating to complete a brief questionnaire (attached). Either I or one of the psychology assistants would be happy to complete the questionnaire with the woman in question. If the woman preferred, her support worker could help her complete it, in which case I will be happy to discuss completion with the support worker.
2. I am also seeking a smaller number of women (approximately 8 in total) who would be willing to be interviewed about their experiences of menstruation. I enclose a consent form which covers issues of confidentiality and also consent to this.

As I am under some time pressure (I need to complete all data collection by mid May!) I would appreciate any help you can give.

If you want to discuss this further, could you phone me?

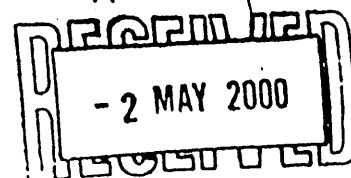
Yours sincerely,

Hedy Ditchfield  
Consultant Clinical Psychologist

encls.



Appendix 4.



*Providing Care in the Community*

Hedy Ditchfield  
Consultant Clinical Psychologist  
Community Learning Disabilities Team

27 April 2000

Dear Ms Ditchfield

I refer to your letter dated 11 April 2000, addressed to who  
presently is on sick leave.

In her absence, I have considered your request which we will be very willing to assist. Unfortunately at present, we have no female (except for one) service users in Learning Disability Service that is of age between 20-45.

The one person who fits this criteria has no communication ability. Therefore in this instance, it seems we will not be able to assist.

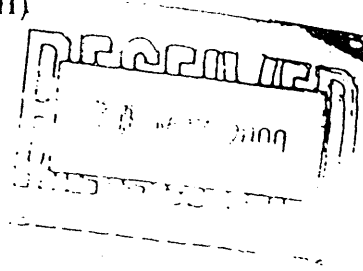
Yours sincerely

Business Development Manager

ETHICAL COMMITTEE (RESEARCH)

25 May. 2000

Dr D Ditchfield  
Adult Learning Disabilities



Dear Dr Ditchfield

Re: The experience of menstruation in women with a learning disability (108/00)

The Ethical Committee (Research) considered and approved the above study at its meeting on 19 May 2000.

Initial approval is given for one year. This will be extended automatically only on completion of annual progress reports on the study when requested by the EC(R). Please note that as Principal Investigator you are responsible for ensuring these reports are sent to us.

Please note that projects which have not commenced within two years of original approval must be re-submitted to the EC(R).

Please let me know if you would like to nominate a specific contact person for future correspondence about this study.

Any serious adverse events which occur in connection with this study should be reported to the Committee using the attached form.

Please quote Study No. 108/00 in all future correspondence.

Yours sincerely,

Research Ethics Coordinator

**MDQ Scales Derived from Menstrual, Pre-menstrual, Inter-menstrual,  
and Worst Menstrual Cycle Factor Analyses**

- |  |  |
|--|--|
| <p>(1) <u>Pain</u></p> <p>Muscle stiffness<br/>Headache<br/>Cramps<br/>Backache<br/>Fatigue<br/>General aches and pains</p>                                      | <p>(5) <u>Impaired Concentration</u></p> <p>Insomnia<br/>Forgetfulness<br/>Confusion<br/>Poor judgement<br/>Difficulty concentrating<br/>Distractible<br/>Minor accidents<br/>Poor motor co-ordination</p> |
| <p>(2) <u>Water Retention</u></p> <p>Weight gain<br/>Skin blemish/disorder<br/>Painful or tender breasts<br/>Swelling</p>  | <p>(6) <u>Behaviour Change</u></p> <p>Poor school or work performance<br/>Take naps, stay in bed<br/>Stay at home<br/>Avoid social activities<br/>Decreased efficiency</p>                                 |
| <p>(3) <u>Autonomic Reactions</u></p> <p>Dizziness, faintness<br/>Cold sweats<br/>Nausea, vomiting<br/>Hot flushes</p>   | <p>(7) <u>Arousal</u></p> <p>Affectionate<br/>Orderliness<br/>Excitement<br/>Feelings of well-being<br/>Bursts of energy, activity</p>   |
| <p>(4) <u>Negative Affect</u></p> <p>Loneliness<br/>Anxiety<br/>Mood swings<br/>Crying<br/>Irritability<br/>Tension<br/>Feeling sad or blue<br/>Restlessness</p> | <p>(8) <u>Control</u></p> <p>Feelings of suffocation<br/>Chest pains<br/>Ringing in the ears<br/>Heart pounding<br/>Numbness, tingling<br/>Blind spots, fuzzy vision</p>                                   |

## Menstrual Distress Questionnaire

## Form C

Identifying Number: \_\_\_\_\_

DOB: \_\_\_\_\_

Today's Date: \_\_\_\_\_

Write the appropriate dates of your most recent menstrual period (flow) in the space marked "A" below. Then write the dates of the menstrual period which preceded the most recent one in the space marked "D".

previous menstrual flow			most recent flow	
from _____	other times during most recent cycle	four days before recent flow	from _____	
to _____			to _____	
D	C	B	A	

On the next two pages is a list of symptoms that women sometimes experience. Please describe your experience of each of these symptoms during the three time periods listed below:

Col. 1 during the four days before your most recent menstrual flow (area B on the diagram).

Col. 2 during your most recent menstrual flow (the dates shown in area A on the diagram below).

Col. 3 during the remainder of your most recent menstrual cycle (area C).

Note: The answers you put in column 1, 2, and 3 should be accurate for your experience during your most recent menstrual cycle. Please do not report your general experience. Also, please report any experience of these symptoms whether or not they seem to you to be related to your menstrual cycle.

For each answer choose the category that best describes your experience of that symptom during that time. Write the number of that category in the space provided. Even if none of the categories is exactly correct, choose the one that best describes your experience. Do not leave any blank spaces.

### Descriptive Categories

0 - No experience of symptoms  
1 - Present, mild  
2 - Present, moderate

3 - Present, strong  
4 - Present, severe

	1 Four days before	2 Most recent flow	3 Remainder of cycle
	A	B	C
1. Muscle stiffness .....	_____	_____	_____
2. Weight gain .....	_____	_____	_____
3. Dizziness, faintness .....	_____	_____	_____
4. Loneliness .....	_____	_____	_____
5. Headache .....	_____	_____	_____
6. Skin blemish or disorder .....	_____	_____	_____
7. Cold sweats .....	_____	_____	_____
8. Anxiety .....	_____	_____	_____
9. Mood swings .....	_____	_____	_____
10. Cramps .....	_____	_____	_____
11. Painful or tender breasts .....	_____	_____	_____
12. Nausea, vomiting .....	_____	_____	_____
13. Crying .....	_____	_____	_____
14. Backache .....	_____	_____	_____
15. Swelling (breasts, abdomen) .....	_____	_____	_____
16. Hot flushes .....	_____	_____	_____
17. Irritability .....	_____	_____	_____
18. Tension .....	_____	_____	_____
19. Fatigue .....	_____	_____	_____
20. Feeling sad or blue .....	_____	_____	_____
21. General aches and pains .....	_____	_____	_____
22. Restlessness .....	_____	_____	_____

	1 Four days before	2 Most recent flow	3 Remainder of cycle
	A	B	C
23. Insomnia .....	_____	_____	_____
24. Poor school or work performance .....	_____	_____	_____
25. Affectionate .....	_____	_____	_____
26. Feelings of suffocation .....	_____	_____	_____
27. Forgetfulness .....	_____	_____	_____
28. Take naps, stay in bed .....	_____	_____	_____
29. Orderliness .....	_____	_____	_____
30. Chest pains .....	_____	_____	_____
31. Confusion .....	_____	_____	_____
32. Poor judgement .....	_____	_____	_____
33. Stay at home .....	_____	_____	_____
34. Excitement .....	_____	_____	_____
35. Ringing in the ears .....	_____	_____	_____
36. Difficulty concentrating .....	_____	_____	_____
37. Avoid social activities.....	_____	_____	_____
38. Feeling of well-being .....	_____	_____	_____
39. Heart pounding .....	_____	_____	_____
40. Distractible .....	_____	_____	_____
41. Decreased efficiency .....	_____	_____	_____
42. Bursts of energy, activity .....	_____	_____	_____
43. Numbness, tingling .....	_____	_____	_____
44. Minor accidents .....	_____	_____	_____
45. Blind spots, fuzzy vision .....	_____	_____	_____
46. Poor motor co-ordination .....	_____	_____	_____
47. Increased appetite .....	_____	_____	_____

MENSTRUAL DISTRESS QUESTIONNAIRE

VISUAL CLIENT GUIDE

0



1



2



3



4



**Shortened Menstrual Distress Questionnaire**

(After Moos 1986 form C)

I would like you to answer the following questions about yourself and your periods:

How old were you when your  
periods started?

\_\_\_\_\_ Yr \_\_\_\_\_ months

How old are you now?

\_\_\_\_\_ Yr \_\_\_\_\_ months

Date of birth

\_\_\_\_\_

How often do you have  
a period (how many days  
from the start of one period  
to the start of the next one?)

\_\_\_\_\_ weeks

\_\_\_\_\_ days

\_\_\_\_\_ don't know

How long does your period last?

\_\_\_\_\_ days

Have you heard of pre-  
menstrual tension or pre-  
menstrual syndrome?

YES NO

Could you say what it means to you?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Who do you live with?  
(please tick one box)

- ☐ On my own
- ☐ With my parents
- ☐ with my partner/husband
- ☐ With others in a residential home
- ☐ Other



Please read the following and mark it as follows:

0 - No experience of symptoms (no change)

1 - Some change (mild)

2 - Moderate change

3 - Considerable (lot of)

4 - Severe change

Do you find you have or feel		4 days before period	During period	Rest of cycle
1.	Insomnia (can't sleep) .....	_____	_____	_____
2.	Affectionate .....	_____	_____	_____
3.	Forgetfulness (forget things) .....	_____	_____	_____
4.	Orderliness (need to tidy up) .....	_____	_____	_____
5.	Confusion .....	_____	_____	_____
6.	Poor judgement (not sure what to do).....	_____	_____	_____
7.	Excitement .....	_____	_____	_____
8.	Difficulty concentrating .....	_____	_____	_____
9.	Feelings of well-being (feel good) .....	_____	_____	_____
10.	Distractible (lose attention) .....	_____	_____	_____
11.	Bursts of energy, activity.....	_____	_____	_____
12.	Minor accidents .....	_____	_____	_____
13.	Poor motor co-ordination (clumsy).....	_____	_____	_____
14.	Increased appetite (feel hungry) .....	_____	_____	_____
15.	Muscle stiffness .....	_____	_____	_____
16.	Weight gain .....	_____	_____	_____
17.	Dizziness, faintness .....	_____	_____	_____
18.	Loneliness.....	_____	_____	_____
19.	Headache .....	_____	_____	_____
20.	Skin changes .....	_____	_____	_____
21.	Cold sweats .....	_____	_____	_____
22.	Anxiety .....	_____	_____	_____
23.	Mood swings .....	_____	_____	_____
24.	Cramps (pains) .....	_____	_____	_____
25.	Painful or tender breasts .....	_____	_____	_____

Do you find you have or feel	4 days before period	During period	Rest of cycle
26. Feel sick .....	_____	_____	_____
27. Cry .....	_____	_____	_____
28. Backache .....	_____	_____	_____
29. Swelling (breasts, tummy) .....	_____	_____	_____
30. Hot flushes .....	_____	_____	_____
31. Irritability (cross) .....	_____	_____	_____
32. Tension .....	_____	_____	_____
33. Tired .....	_____	_____	_____
34. Feeling sad or unhappy .....	_____	_____	_____
35. General aches and pains .....	_____	_____	_____
36. Restlessness (can't settle) .....	_____	_____	_____

Ethics Committee Reference Numbers EC201 and 108/00

Research into the experience of the menstrual cycle  
in women with a learning disability

***INFORMATION SHEET FOR WOMEN***

**What is the Study about?**

This study is to find out about the changes that may happen to women when they are having a period.

**What happens if I want to take part?**

You will need to complete a short questionnaire about your last period. This takes about 15 minutes and is private. You do not have to give your name and no one will know who you are.

Hedy Ditchfield or one of the other psychologists in Lambeth would be happy to help you or you could ask your key worker.

Once completed the study will be written up and sent to local doctors/practice nurses.

It is hoped that it will lead to better care for women.

If you would like to take part, could you let us know by phoning

**Hedy Ditchfield on 020 7411 2960  
or return the slip below**

-----

Please return to 340 Brixton Road, Brixton, London SW9 7AA

I would be happy to take part in the study about periods.

Name: \_\_\_\_\_

I can be contacted on: \_\_\_\_\_

**CONSENT FORM FOR PARTICIPATION IN RESEARCH PROJECTS & CLINICAL TRIALS**

<b>Title of Project:</b> <b>The Experience of menstruation in women with a learning disability</b>	
<b>Principal Investigator:</b> <b>Hedy Ditchfield</b> <b>Other Investigator/s</b> <b>enrolling patients:</b>	<b>Ethics Committee</b> <b>Code No:</b> EC99/201 + 108/00
<b>Outline explanation:</b> I am interested in how women with a learning disability feel about having periods. I particularly want to find out if they know as much as women without a learning disability and if their feelings are the same.	
<b>Do you have any questions so far?</b>  This will involve meeting with me for about half an hour and talking about having periods. With your permission, we would like to record this meeting on an audio-tape. You can stop this at any time. Only I will listen to the tape. No one will know your name or who you are.  You can have a copy of the tape if you like. The tape will be wiped clean (erased) after the study is finished. Whilst the research is in progress, the tapes will be kept in a safe place.	
<b>Do you have any questions?</b>  When the study is finished the results will be written up. No one will know who you are in this report. The findings will be sent to local Doctors. It may lead to better care for women with learning disabilities. You can have a copy of the report if you want it.	
I know the aims of the study. They have been explained to me. I am happy to take part in the study. I agree to the talk being tape recorded. I know what I say will be private and no one will know who I am from the study. I know the tapes will not be kept after the end of the study. They will be destroyed. I can have a copy of the report at the end of the study. I can also have a copy of the tape if I want it.	
<b>I (name)</b> _____  <b>of (address)</b> _____  _____	
I hereby consent to take part in the above investigation, the nature and purpose of which have been explained to me. Any questions I wished to ask have been answered to my satisfaction. I understand that I may withdraw from the investigation at any stage without necessarily giving a reason for doing so and that this will in no way affect the care I receive as a patient.	
<b>SIGNED (Volunteer)</b>	<b>Date</b>
<b>(Witness, where appropriate)</b>	<b>Date</b>

3 copies required - one for the researcher, one for patient/volunteer, one for patient's notes

## **SEMI STRUCTURED INTERVIEW SCHEDULE**

The word used to describe menstruation was generally ascertained at the time of gaining consent to participation in the study. The preferred term was then used in the interview.

### **① Can you tell me how old you were when you started your periods?**

#### **Prompt questions:**

Do you know when your next period/monthly will be?  
How long do they last?  
How do you manage them?  
What help do you need?  
Do you use pads or tampons?

### **② Can you tell me what you felt when your periods started?**

#### **Prompt questions:**

Who did you tell?  
What did you do?  
What help did you have?

### **③ What information did you have about periods when you started?**

#### **Prompt questions:**

How did you learn?  
Who did you talk to?

④ **How do you feel about periods now?**

**Prompt questions:**

Is there anything you don't do when you have a period that you would do at other times?

Who do you tell about periods?

What is good about having periods?

Is there anything you don't like?

⑤ **Can you tell me how you think periods link up with having babies?**

**Prompt questions:**

What is the connection between periods and having babies?

Can you tell me more about the connection with sex?

⑥ **How do you feel just before your periods?**

**Prompt questions:**

Have you heard of pre-menstrual syndrome (PMT or PMS)?

What does it mean to you?

⑦ **Is there anything else you would like to say?**

Looking back, did you know what was happening when your periods started?

Not at first. I was so scared. I didn't want to tell my mum, I was too scared so I told my older sister, I said I have just come on and she had some pads and knew what to do. I was too scared to tell my mum What were you afraid of? That she might snap at me, I think she would have done that. I think my mum wouldn't understand.

What would she not understand?

Well I <sup>thought</sup> she might say that something else might have burst in my stomach that why I didn't want to tell her. That's what she probably think about it, that's why I didn't want to talk to her. I was too afraid. Then my sister told my mum and my mum just said 'oh that's fine'. But since I come on at 16 but I was 17 before I told my mum, about 17 or 18 when I was getting older but I couldn't tell her before. You mean you kept it secret from her and she didn't ask? That's right

So who told you about periods and what is happening?

My sisters told me. They had it easier and what puzzles me is that I have bad periods and they don't, it's only me in the family that has it bad. I mean I didn't know about periods until just before and they told me what happens, that the blood circulates in the stomach and that you will have belly ache and cramps and that is how you start a period. I was afraid when I heard that I was. Then they told me where the blood would come out and I was scared and I went 'Oooh, blood, blood, blood.'

What did you think was happening?

I don't know but it made me feel like an adult like a woman. Was that good? Yes that was good

lack of knowledge

fear / privacy

anxiety

Secrets

not understood

uncertainty

fear

uncertainty

fantasy of  
something  
dreadful  
happening  
misinformation

Secrets

how did  
it start

Sources of info.

puzzled  
Companions

Ref. family

Attributions  
info. knowledge  
misinfo.

fear  
anxiety

True  
felt like a  
woman

fear

not tell

fear anxiety

privacy / identity

20

Identity

25  
knowledge  
fear

30  
fear

Identification  
with other women  
35  
True identity

# Identification as a woman

Could you say why we have periods?  
What did your sisters say?

Natural  
something that  
happens  
normal event

They said it was nature, that every woman  
in this country has periods and it's natural.  
Do you know why we have them though?  
I'm not sure I don't know really. It's easier  
in life to have periods than having babies but  
I know there is some link. I had a hard time  
with my baby and they had to cut me open  
as her head was stuck in the water.

Natural  
= women

uncertainty  
confusion

Have you any idea of the link between  
periods and babies?

Change  
uncertainty  
confusion  
lack of knowledge  
anxiety

Well your body is changing but... no... no I  
don't. I mean I know when you haven't  
come on then you might be pregnant, that's  
what it is but no... but when I get stressed  
my periods stop as well because that  
happened to me once and I thought I was  
pregnant but I don't really know about that,  
I mean how periods link with babies, I don't  
know. Do you think [Community nurse]  
would help me? Could you ask her? [assent]

Sexuality  
uncertainty

Confusion  
lack of knowledge

Source of info ??

You said that your sisters told you a lot.  
Could you say where else you learnt  
about periods?

Access to  
info  
lack of understanding  
lack of  
control of  
info.

Well, at school but we didn't get much  
information and I didn't understand all the  
time. You couldn't ask questions there. I  
mean I didn't get much information, I  
haven't read no books or whatever.

knowledge  
understanding

Access to info.

How do you feel about having periods?

Revelation  
Blood  
Exhaustion

Comparison

needing

They are horrible, really horrible. I don't  
like them at all. I lose a lot of blood and I  
get clots, heavy clots and they tire me out 25  
so I am exhausted. My next door neighbour  
she gets the same pains like me and she  
understands. I'm the worst one for losing  
blood and I take it out on everyone. I don't  
always mean it but someone spoke to me and 26  
I went 'of shut up, go away'. I mean I have  
a lot on my mind. Like I told my boyfriend

Emotional response  
to menstruation  
Debilitation

Social comparison

Heavy "worst"  
menstruation



Suffer (lack of it!) mood changes

how bad I was and he said 'Oh, it's as well I didn't come round then, isn't it' He knows about my tempers when I have a period.

Mood

**It sounds as if periods have a big effect on your life?**

Impact on life

Yes they do. I mean I don't even want to go to the shops or see anyone or get out of bed. The first 2 days I get cold shakes, really shaky and very cold like ice and I don't want to get up. I just get in a hot bath on the 3<sup>rd</sup> day and warm myself up. I hate them. **Is there anything you like?** No nothing. I just want the operation to stop them. I sit down and cry and I worry about my boyfriend as he doesn't come round. I asked him once to go to the chemist to get me a packet of sanitary towels, the green ones and he went 'oh I couldn't do that, I'd be too embarrassed' and he went [made noise] so I said 'don't put yourself out, I'll go' even though I was in agony. He always misses them, he's in work or something so he'd not be much help but he does know about them. I think he understands. And I feel sick, I want to vomit. They are just a problem to me. I want this operation so I don't have no more periods and no more pains. P [Community nurse] she knows what I'm like, she's seen me then. Sometimes I use more than a whole packet and I use the whole lot and sometimes they leak and then it's not good. That's how bad I am. It does my head in it does.

5 Impact on life

→ Sensitive

10

Desires

15

Worrying

Pain

20

Agony

Sometime

problems

Worrying

Dislike revision

Surgery Anxiously

lack of support

pain mixed agenda

lack

Sick vomit problems help

Surgery

Management

Want to sleep

**Tell me more about this operation?**

My friend had it, she had the operation and she's happy now as she doesn't have pains or periods. I wouldn't mind that

Sleep

## Superordinate Theme One

Subordinate Themes	Examples	No. of Refs.	No. of Partpnts
Labelling Menstruation	"What does it mean?" Laura 1/4 "It's just your monthlies" (Lois 1/25) "It's a period" Claire 1/10	18	11
PMS/PMT	"I've never heard of that" (Marie 4/15) "I haven't had any of that – never" Jodie 5/10 "You get that when you're older don't you?" Kate 3/26 "No what's that?" Rachel 6/11	11	6
Preparedness for Menarche Not prepared	"I didn't know what was happening and went yuk, yuk" (Rachel 2/25) "I was scared to tell my mum" (Moirira 2/4) "I told my mum I must have cut myself....I'm bleeding" Lucy 3/15 "My mum left when we was kids....I didn't know" Lois 2/20	15	9
Prepared	"I was expecting it" (Sara, 2/20) "My mum was pretty helpful" Marie 2/3	3	2
Knowledge	"The blood circulates in the stomach" Moira 2/10 "It's just your body changing" Lois 3/18 "I don't know why we have periods" Claire 3/12 "You have a period to get rid of the old blood" Carrie 4/8 "It's to do with how much oxygen you have in your body" Jodie 4/32 "I don't know what's happening" (Marie 3/4)	26	10
Access to Information	"Give us something with leaflets" (Marie 3/12) "I'd like to learn about a woman's body" (Jodie 6/10) "There wasn't any information....I'd like to know more (Claire 2/22) "We're not told properly" Rachel 4/22 "I think people deliberately don't give us enough information" Laura 6/19	23	10

## Superordinate Theme Two

Subordinate Themes	Examples	No. of Refs.	No. of Partpnts
Experiences of Pain	<p>"The pain shoots across my stomach" (Rachel 2/3)</p> <p>"In agony" (Moirira 4/19)</p> <p>"The pain is everywhere in your body" (Lois 4/1)</p> <p>"Feels like the bones are being pulled out of me" (Claire 1/5)</p>	53	10
Experiences of Mennaraghia	<p>"I have to change pads 6 or 7 times a night" (Carrie 5/20)</p> <p>"I get really heavy clots" (Moirira 3/25)</p> <p>"I have to put on 2 pads" (Laura 6/10)</p> <p>"There's blood all in the bed" (Claire 3/8)</p> <p>"It used to go through my trousers" (Rachel 2/17)</p>	48	9
Adverse Impaction Mood	<p>"It makes you really down" (Lois 2/6)</p> <p>"I get really fed up and cry" (Sara 3/5)</p> <p>"I take it out on everyone" (Moirira 3/27)</p> <p>"I start being rude to people" (Laura 2/15)</p>	42	10
Other Somatic Experiences	<p>"I was bringing up vomit, vomit, vomit" (Rachel 2/26)</p> <p>"I feel sick and hot" (Kate 4/32)</p> <p>"I used to black out every month" (Jodie 1/32)</p> <p>"I can't walk as my legs go like jelly" (Lucy 1/23)</p>	23	8

### Superordinate Theme Three

Subordinate Themes	Examples	No. of Refs.	No. of Partpnts
Management of Menstruation	"I use pads, not them tampons" (Moira 1/12) "I don't like tampax, they're too dangerous.... I use ordinary pads" (Carrie 6/5) "I have to take spare clothes to work" (Kate 4/10) "I keep old pairs of knickers for my periods" (Jodie 2/20)	32	11
Coping Strategies	"I have this relaxation tape" (Laura 2/9) "I drink hot tea and drinking chocolate" (Moira 5/12) "A hot bubble bath" (Lois 5/1) "Take evening primrose oil" (Carrie 5/7) "Take panadol" (Lucy 1/20)	26	9
Need for Support	"I think we should get more help" (Lucy 6/17) "I was in a children's home, no-one helped" (Kate 1/18) "He's not very sympathetic" (Sara 3/6) "My Dad didn't want to know" (Claire 2/22)	14	8
Relationship with Professionals	"I would like doctors to help me..." (Claire 4/12) "They use words you don't understand" (Kate 4/16) "My doctor nags me" (Sara 4/11) "Nothing stayed private..." Carrie 7/5	26	7
Restriction of Activities	"I can't go swimming" Kate 4/2 "I don't feel like exercise" Carrie 4/15 "I can't go on my exercise bike – pins and needles" Claire 3/25	5	4

#### Superordinate Theme Four: Attitudes to Menstruation

Subordinate Theme	Examples from Test	No. of Participants
Response to menarche	<p>"I was scared"</p> <p>"I didn't know anything"</p> <p>"I thought 'yuk, I'm going to hate this'"</p> <p>"I felt absolutely awful"</p>	10
Current attitudes	<p>"I hate them"</p> <p>"There's nothing good about them"</p> <p>"I just want them to stop"</p> <p>"I wish I'd been a man, they don't get periods"</p>	10
positive	<p>"They are OK I suppose"</p>	1
Influence of others	<p>"Boys used to laugh"</p> <p>"He isn't very sympathetic"</p> <p>"Staff talk about it"</p> <p>"They treat me like a baby"</p>	6

### Superordinate Theme Five: Impact on Identity

Subordinate Themes	Examples for Text	No. of Participants
Identification with other women	<p>"It's something us women have to suffer"</p> <p>"Us women put up with it"</p>	6
Adult status	<p>"It's a ladies thing"</p> <p>It's getting to be grown up"</p> <p>"You're grown up"</p>	6
Social comparisons	<p>"My friend has them bad, like me"</p> <p>"I have them worse than my sisters"</p> <p>"My sister can use Tampax....I can't"</p>	5
Staff control	<p>"I have to tell M....who then tells D...."</p> <p>"Staff treat us like babies"</p> <p>"Staff talk amongst themselves about us....our periods"</p>	5

### Superordinate Theme Six: Relationship with Sexuality

Subordinate Themes	Examples for Text	No. of Participants
Uncertainty	<p>"I know there is a link between periods and pregnancy but I don't know what"</p> <p>"It's to stop you having children"</p> <p>"If I didn't have a period my hormones would want me to get pregnant"</p> <p>"I know you have a baby when the time is right"</p> <p>"I don't know about intercourse"</p>	11
Sexual identity	<p>"When a fellow does what he does"</p> <p>"It's very embarrassing"</p> <p>"You can't have sex when you have a period"</p> <p>"When he puts his penis in you"</p> <p>"Talking for me is better than intercourse"</p>	9

## **Debriefing Information**

**(Given verbally to participants)**

Thank you very much for meeting with me and talking with me. What you have said has been very helpful.

I will now type it up. Do you want the tape? If not, I will wipe it clean. I will then look at what you said and compare it with the experiences of the other women who have talked with me. No one will know who you are or where you live in these reports.

After that I will write it up and copies will be sent to you or your care manager. Would you like a copy?

I will also write a report, which will be sent to General Practitioners and Practice Nurses. It may help them understand your experiences more.

Do you have any questions?

Is there anything else you would like to say?

If you feel you would like to talk to someone about your periods then one of the community nurses would be happy to meet with you.

You do not have to decide now. If you would like help in the future then you or your support worker could contact them at the Learning Disabilities Team base.

Is there anything else you would like to say or ask?

Thank you again for your help.

Hedy Ditchfield

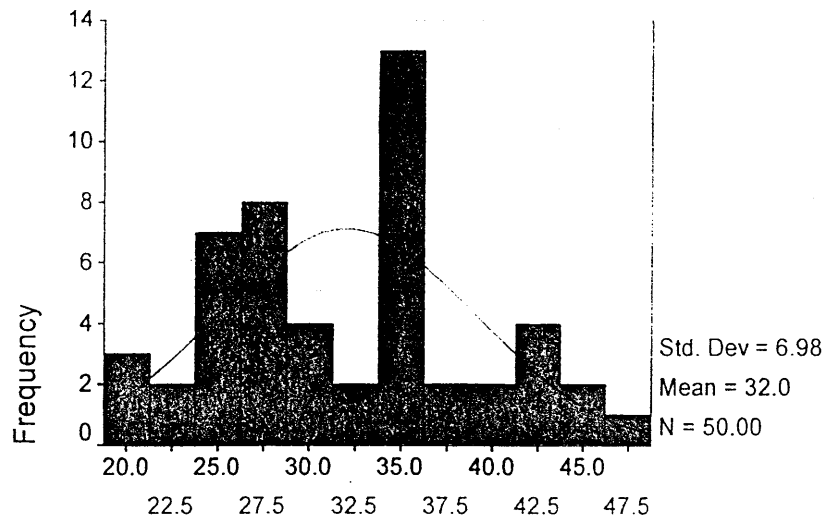


## Frequencies

### Histogram

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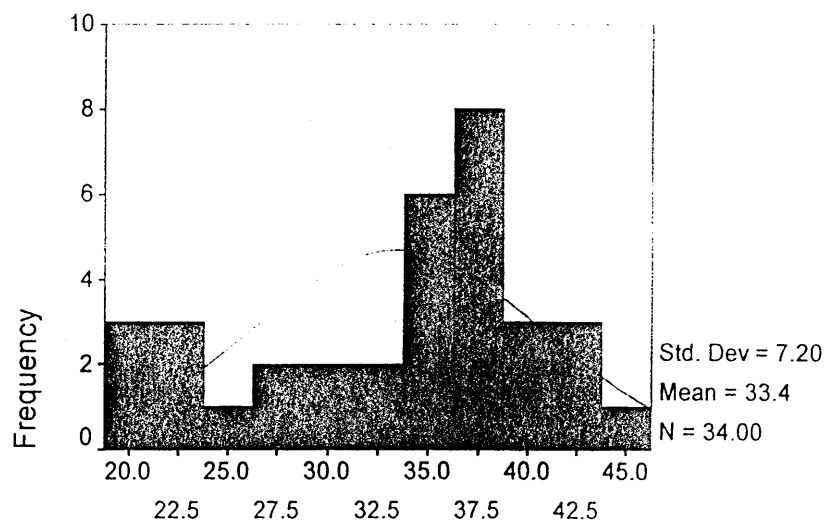
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AGE

AGE

GROUPS: 2 client



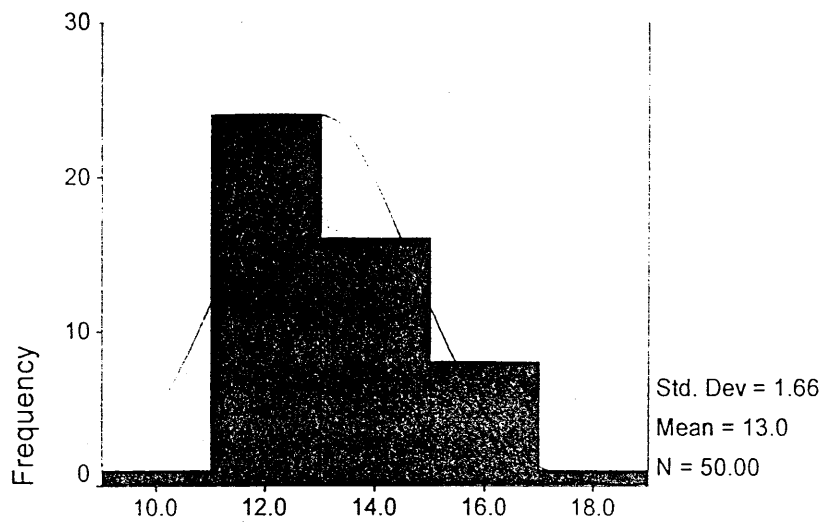
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## Frequencies

### Histogram

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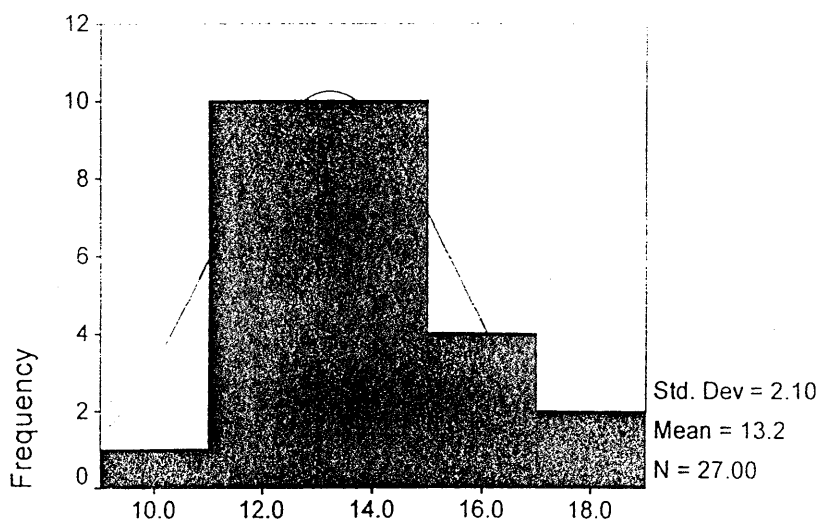
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onsetage

onsetage

GROUPS: 2 client



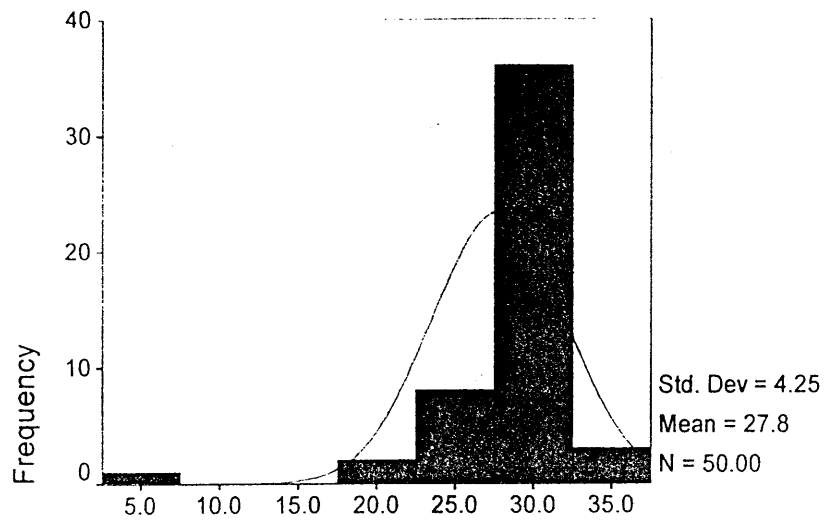
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## Frequencies

### Histogram

lengthofcycle

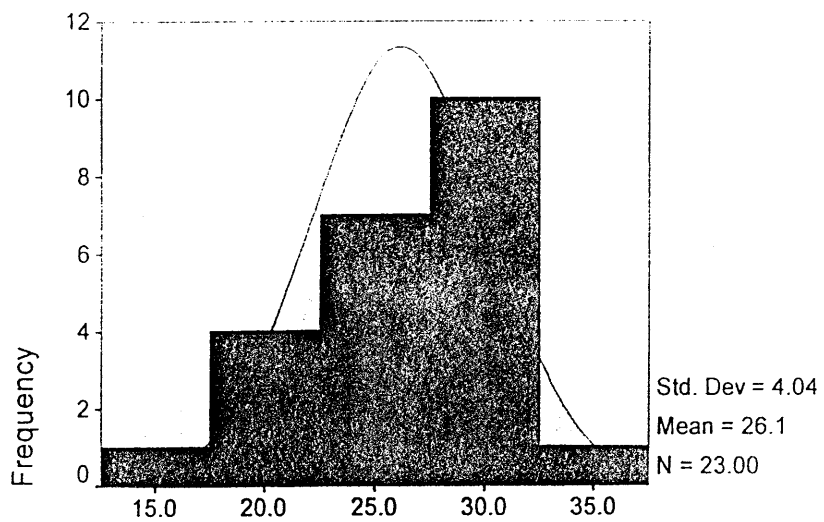
GROUPS: 1 controls



lengthofcycle

lengthofcycle

GROUPS: 2 client



lengthofcycle

# Frequencies

## Histogram

